

MANAGING ASTHMA AT SCHOOL: THE PERCEPTIONS OF CHILDREN AND SCHOOL STAFF.

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Abstract.

This thesis presents the findings of a mixed methods study exploring the perceptions of children and school staff managing asthma in seven Bristol primary schools. Asthma is the most common chronic disease of childhood, affecting 1 in 10 children and is consequently the most frequent chronic disease that school staff will encounter in school or a school related setting. Children spend a 1/5 of their childhood in school or school related locations and are thus managing their asthma without the direct aid of parents/carers during this time.

The research aim was to explore how asthma was managed in these schools from both the view point of school staff (both teachers and school support staff) and pupils with asthma. The use of a mixed methods approach facilitated integration of qualitative and quantitative research methods and resulted in greater exploration of the phenomenon of managing asthma in school than one approach alone could have provided. Discrete qualitative research interviews conducted with children and school staff together with quantitative surveys of both child perceived Health Related Quality of Life (HRQoL) and school asthma policies are presented in this thesis.

Findings within this research indicated that generally school staff were unaware of how to help in the management of pupil asthma. There were significant obstacles within schools, in part created by school staff that pupils with asthma had to overcome when trying to manage their asthma at school. Pupils perceived that they were experiencing a high level of asthma associated morbidity and a significant reduction in HRQoL. Children discussed a range of coping strategies that they used in their daily school management of their asthma which significantly limited their interactions with peers and school staff and potentially had lifelong consequences.

These findings were not those suggested by the literature, which suggest that asthma is understood in school and clearly managed. This research illustrates that managing asthma in school is a complex interplay of situational factors, expectations and dependent upon the ability of school staff and children to recognize not just asthma warning signs, but to facilitate 'good' daily asthma management.

This thesis is split into two volumes.

Volume 1: Front cover, contents – Chapter six inclusive.

Volume 2: Chapter seven – Appendix ix inclusive.

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I also wish to acknowledge my former supervision team Professor Susan Roulstone and Dr Toity Deave.

Finally and most significantly I want to thank my family, in particular my children who have paid a huge and profound personal price.

Dedication.

To the memory of Sam Linton.

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1: Introduction.

1:1 Aims of the introduction.

This introduction will describe the background of the researcher and interest in this topic. The chapter will then progress to explain the overall structure of this thesis and the subject of the research, the nature of the methodology and the research setting will be briefly described. Relevant research studies will be briefly outlined which will help provide the research framework that this thesis rests within. Similarly the key government and local policies will be referred to which help provide the context for this research. Within this chapter there is a consideration of the significance of this research topic and the research aims.

1:2 Background of the researcher.

The incentive for this research arose from several sources; in summary these are located in professional experiences both in health and education and my previous research experience. My professional background is that of a graduate registered general nurse and I have an MSc in Human and Applied Physiology together with a wide variety of clinical practice of *circa* 20 years. I have worked in a number of health authorities in both primary and secondary care settings and my last clinical appointment was as a respiratory nurse specialist and clinical manager of both adults' and children's respiratory services. During this appointment I spent a significant amount of my time working with children, their families/ carers addressing respiratory related issues. My specific interest at this point

was asthma. In my clinical interactions with children and their families I had noted that how they described asthma and its management in schools was not comparable to my experiences as a teacher and a researcher in secondary schools.

This clinical appointment followed upon my appointment to run, design organize and deliver a two year pragmatic randomized trial (Salisbury *et al.* 2002, Francis 2001a) investigating if asthma focussed clinics in secondary schools would improve children's asthma associated well being. This gave me daily access to a number of secondary schools and I had noted that there was some cause for concern as a health professional and also a registered teacher regarding asthma and its management in these secondary schools (Francis 2001a). Prior to my appointment to run this research I gained my Post Graduate Certificate in Education (PGCE) from Exeter University. This involved significant length of time in teaching practice in secondary schools in Cornwall, during which I had noted that in my opinion management of children's chronic health needs in school was limited.

These observations together with my practical and clinical experiences and my growing expertise and interest in asthma see Francis 2006, Francis 2004, Francis 2001a, Francis 2001b, Francis 2000a, Francis 2000b, Francis 2000c; provided the milieu within which the research questions for this thesis were formed.

1:3 Résumé of relevant key policy and the principles of asthma management.

Asthma is a common disease (Global Initiative for Asthma (GINA) 2007), and it affects between 10 and 15% of children in the UK (National Asthma Campaign 2004). Asthma causes significant morbidity if not effectively

managed, this includes breathlessness, wheezing, coughing and an associated inability to participate in a variety of activities (British Thoracic Society/ Scottish Intercollegiate Guidelines Network – asthma guidelines 2009). These and other symptoms can result in severe life threatening conditions and in the UK *circa* 1500 people die as a direct consequence of asthma per year (General Registrar’s Office 2002).

Health care professionals are given direction in their management of asthma in the UK from guidelines such as the “British Thoracic Society- Scottish Intercollegiate Guidelines Network Group (BTS/SIGN) 2009 Guidelines Upon the Management of Asthma.” These guidelines provide suggestions for best practice following systematic review of clinical and academic research within the field of asthma. Using the SIGN convention evidence is ranked and statements concerning the management of asthma within these guidelines are created. Aims of asthma management are to ameliorate symptoms with the use of adequate therapy and advice such that asthma has no affect upon the individual’s daily participation in life. These guidelines and earlier editions state that the person with asthma wherever possible should be in a position to manage their own disease. With adequate supported knowledge this should be possible for young people and children.

There is guidance available for schools regarding the management of asthma, for example, managing medication in school (DfES 2005) and managing children’s chronic health conditions (DCSF 2007a, DfE 2010). This guidance suggests principles of good practice that are designed to enable children with chronic ill health to maximise their engagement with school and the school environment.

Children attend school for *circa* 1/5 of their childhood (DCSF 2007a). During their time in school children with asthma are managing their asthma themselves or relying upon the school staff to manage their

asthma or using both strategies. Management of chronic ill health in schools is addressed in part by guidance issued from the then Department for Children, Schools and Families (DCSF) concerning management of medication in schools and chronic ill health (DCSF 2004). Local education departments within local authorities together with each school are responsible for ensuring that school specific policies are in place to address the care of children with chronic ill health.

The first release of BTS/SIGN asthma guidelines occurred in 1999 and almost annual updates were provided thereafter. These updates together with the guidance of the then Department for Children, Schools and Families (DCSF formally the DfEE¹) and the concurrent release of policy documents such as the DCSF “children’s plan- building brighter futures” (2007a), seemed to provide further drivers supporting the rationale for this research to be conducted.

Consequently, in consideration of this overview and background of the researcher this thesis is constructed in order to put forward and consider answers, thoughts and discussion upon children and school staff’s experiences of asthma in primary school settings.

1:4 Generation of the research thesis title and research questions.

All of the factors listed in section 1:2 lead to an interest in how asthma was managed in schools. The aim was to try and understand what it was like to

¹ The department with responsibility for education in H.M. Government has undergone a number of name changes in the time frame referred to in this thesis. These are listed chronologically as: Department for Education and Environment (DfEE); Department for Children, Schools, and Families (DCSF); Department for Education (DfE). In this thesis the relevant abbreviation relating to the name for the current ‘Department of Education’ as it was at the time of the policy or guidance referred to will be used, thus the three abbreviations listed above will exist in this thesis, and should be considered to relate to the government department with responsibility for education at that time.

have and manage asthma in a primary school setting. The research questions focus upon the experience of children and school staff in the management of asthma in school and, what policies and practices exist in the school environment in relation to pupil asthma management. The research questions have not been altered since initial registration of this research (see section 2:6.3 and 2:6.4 which presents the research questions in consideration of the relevant research literature). They were created as a result of the narrated experiences of children in school as told to me in my clinical roles, my own clinical and research experience in this area and the review of the relevant research literature. Also I had noted that in my research within secondary schools I often encountered children of 11 -12 years of age who had already adopted specific views and attitudes towards asthma and its management that appeared already entrenched.

Thus my previous research and clinical practice created many more questions than answers and I wanted to explore what was happening in primary schools with respect to children with asthma.

1:4.1 Research Aim

To study aspects of the experience of how asthma is managed in primary education in Bristol.

1:4.1i Research Questions.

- 1) What are children's experiences of asthma within primary schooling?

- 2) What policies do schools have in place concerning the management of child asthma?

- 3) How do these policies compare with National Asthma Guidelines?
- 4) Are there differences between schools concerning their asthma management?
- 5) What are the experiences of teachers and school support workers concerning their involvement with child asthma management?

1:4.2 Choice of research location.

Location for this research was determined to be within primary schools; arising from the fact that the researcher's previous research had focussed upon secondary schools, with unpublished inferences from this research indicating that early years schooling significantly influenced adolescent views. Together with my clinical practice suggested that primary schools and early years schooling were significant factors in children's asthma management. This would allow exploration in context of both school staff and children's experiences of asthma management and generation of context specific information. Bristol primary schools were chosen both for pragmatic reasons and also knowledge of asthma prevalence statistics associated with Bristol. This will be explored in more detail in the methodology chapter. In essence Bristol is a small city and county with, in the years 2007-2009, 117 infant, junior and primary schools in total. Throughout this thesis the term 'primary school' is used in connection with reference to both school and school staff related information .

The high asthma prevalence (and thus a high potential number of children to recruit as research participants) and compact geographical locality of

Bristol primary schools led to choosing Bristol as a suitable location for this research.

1:5 Overall structure of this thesis.

This thesis follows a mixed methods design in its construction. Mixed methods allow the use of qualitative and quantitative research methods within the same research in a synthesized approach in order to answer the research questions. The structure and nature of the research questions within this thesis requires using several differing strands of enquiry in order to address and answer them. These considerations led to the following construction of this thesis. There are nine chapters in this thesis (plus appendices).

The introduction assumes a fairly conventional structure, followed by the review of the relevant literature. The literature review presents the context and general overview of the relevant literature, identifying areas where there is limited information available and relating these gaps in the literature to the generation of the research questions. This information is presented adding value to the considered argument for the generation of this thesis and justification for this research.

Then the methodology chapter follows, which addresses the key tenets of using a mixed methods approach to gather this research data. The methodology chapter explores the key points of a 'mixed methods' approach and the ontology and epistemology associated with it together with those of the researcher. It concludes with a brief overview of the methods used to gather the research data.

The subsequent research findings chapters (chapters four – seven) then present the research data and findings with each chapter commencing with the relevant methodology and methods used to gain those research findings. The first of these chapters is that exploring school staff experiences in the management of child asthma in the school setting. This chapter includes both the qualitative methods and findings gained from the research interviews with school staff.

The next chapter presents methods and the data obtained relating to the existence and use of school asthma policies. The following chapter discusses children's experiences in their management of asthma in school and also contains methodology and methods associated with the generation of this research data.

The final research findings chapter (chapter seven) also contains detailed consideration of the methods and methodology used to gain quality of life research data and focuses upon presenting children's perceptions of the influence of asthma upon their quality of life.

Chapter eight then presents an integrated overview of how asthma is experienced and managed in two schools, both from the viewpoint of school staff and the children. This is generated by interrelating together findings from all of the data collection activities. This chapter was written in the consideration that it would appear there are both differences and similarities apparent within schools from the research findings and data obtained. Thus comparing and contrasting two schools provides an overview of the key research themes and data in context. This chapter demonstrates the value of a mixed methods approach, using differing strands of enquiry in order to present a synthesized, integrated discussion of the phenomenon of managing asthma in primary school.

The final chapter considers how the research findings and data address the research questions. This discussion chapter considers the contribution of this research and the generation of new knowledge in relation to the field of asthma in schools. Methodological issues and a critical discussion of the inherent problems of an accepted method of inquiry, the use of a specific quality of life questionnaire, into children's perception of asthma associated quality of life are presented.

Development of the researcher is demonstrated throughout this thesis. The value of mixed methods research and the decision to use this method of enquiry is discussed. Finally the whole thesis is considered in context against the thesis title and assessed against the aims of the research, contribution to the subject area and development of new knowledge.

2: Review of the Literature.

2:1 Chapter structure.

This review of the literature tends to follow a 'narrative approach' (Pawson and Bellaby 2007 chapter in Pope, Mays and Popay 2007) in its construction. Characteristics of this approach include an 'expert' or 'interested person' who collects together studies they are familiar with and attempts to make sense of the cumulative evidence by summarizing and interpreting that literature. Pope, Mays and Popay (2007 page 4) state that this is a useful approach to adopt and "still forms the basis of most doctoral theses". Development and critical review of the chosen papers presented in this thesis and the skills of gathering information and reviewing the findings are demonstrated in this chapter and in appendix i. Appendix i summarizes the logical approach used and refers to the critical framework used to gather and evaluate both the credibility and suitability of the literature presented in this review. This method does not follow the criteria of a Systematic Literature Review, but does attempt to reduce inclusion of literature that is methodologically flawed and reduce the issue of author bias in the literature presented.

The review process of the presented literature has been undertaken analytically, using a methodical approach to the inclusion and exclusion of work and following logical frameworks. Such frameworks used for example, are those as suggested by Polit, Beck and Hungler (2001), Parahoo (2006) and the specifically designed framework tools available

from the Critical Appraisal Tool Programme (2010) were used in the majority of instances; all are available online. Furthermore the literature reviewed was increased by making use of a number of resources available for example electronic databases, paper journals, books and information available upon the World Wide Web.

Careful consideration has been given to the inclusion of 'grey literature' in some sections of this literature review when either there has been little else available or it is a source of information that would be used by all the research subjects in this thesis. In part this adds argument to the justification of this thesis and the need for the creation of more rigorous research documents. The inclusion of grey literature reflects the acknowledgement that the World Wide Web has allowed access to useful multimedia, multi-textual information routinely accessed by parents and children concerning their own health (Sim *et al.* 2007). Certainly some information available upon the World Wide Web is uncensored, unregulated and incorrect. However, many world web sites provide accurate, peer reviewed, expert information aimed at providing resources for expert researchers, lay people and health professionals. In the context of asthma such world wide web sites for example include those provided by the British Thoracic Society (BTS), Asthma UK (formally the National Asthma Campaign), Department of Health (DH), the National Health Service (NHS) and the Social Care Institute of Excellence (SCIE 2010) (online). These online web sites used skilfully can provide reliable and useful information and the skill of selecting web based possibly 'grey' literature relies upon careful consideration of the document, experience and understanding of the researcher in the field in question and knowledge centred around the accepted and established literature (see Appendix ii (web site review documentation)). However, caveats and care should always be applied and the grey literature that is included in this thesis is clearly identified as such.

This literature review will present a considered discussion of the incidence and prevalence of asthma globally and within England and children specifically. The key policies (both health care related and educationally focused) associated with asthma management within England will be reviewed. Following this a consideration of the symptoms of asthma, their effects upon childhood and how asthma is perceived and experienced by children will be discussed. The importance of school and schooling and the role that school (and school staff) have associated with child development and chronic child health management is also considered.

The concluding sections of this literature review then discuss how the current literature provides: the rationale for the generation of this thesis research questions; choice of research location; choice of research methodology (to be discussed in greater detail in subsequent chapters) and hence the justification for this work.

2:2 Asthma – an indication of its prevalence and incidence globally, within the UK and then more specifically within England.

Asthma is a chronic lung condition, affecting people of all ages and represents a serious global health problem (Global Initiative for Asthma (GINA) 2004, 2007). It is estimated one in twenty people in the world now have asthma, thus affecting an estimated 300 million people world-wide, with an additional 100 million cases predicted by 2025 (Masoli *et al.* 2004). A decade ago the World Health Organisation (WHO) (2000) estimated that asthma deaths exceeded 180,000 a year. These deaths should be almost entirely avoidable (Viegi *et al.* 2003, British Thoracic Society/ SIGN 2009 (available online), GINA 2004).

Asthma causes significant morbidity and mortality within the United Kingdom (UK) (GINA 2004). It is stated that the UK and the Republic of Ireland have amongst the highest prevalence rates of asthma in the world (GINA 2006). Figures vary but between 8% (Smith and Partridge 2000) and 10% (GINA 2004) of the population has symptomatic asthma. It is the most common long term condition in childhood affecting 1.1 million children in the UK (approximately 1 in 10) (National Asthma Campaign (NAC) 2004). 5.4 million people in the UK in 2009 received asthma associated medication for the treatment of asthma (Asthma UK 2010a) (online).

The estimated prevalence rate for asthma in children in the UK reduced from between 12 and 15% in 2001 (Health Survey for England 2001) to between 10 and 13% in 2004 (NAC 2004). However, these figures have remained fairly static over the last five years (Asthma UK (2009b)). Prior to this, the incidence, prevalence and severity of asthma within the UK increased substantially in the 1990s (Majeed & Mosser 1998), with childhood (2- 16 years of age) asthma becoming more common (Ryan & Freeman 1991, International Study of Asthma and Allergy in Childhood (ISAAC) 1998). In the late 1990s asthma was cited as the most common chronic disease in childhood, with an estimated prevalence of between 8 – 14% (ISAAC 1998). ISAAC studies have suggested that the UK along with New Zealand, Australia and the Republic of Ireland have a mean prevalence of asthma in childhood between 29- 32%. Within Bristol, this prevalence may have been as high as 33% of adolescents (11- 16 years of age) experiencing asthma or asthma related symptoms (Francis 2001a, Salisbury *et al.* 2002).

There is some evidence that there is an under- diagnosis of asthma in childhood, considering the incidence of symptoms associated with asthma, for example, wheezing; in 2002 27.5% of 12-14 year olds in the

UK had wheezed in the past week (Anderson *et al.* 2004). Although this was a reduction in figures from 33.9% in 1995 (ISAAC 1998) it still indicates that there is a greater incidence of symptoms than confirmed diagnosis of asthma in childhood.

Associated with the reduction in incidence of asthma in childhood there is an increase in incidence of asthma in adulthood (Asthma UK 2005). Whether this is because it relates to the fact that children in the 1990s have grown into adults or other factors such as diagnosis becoming more effective in adulthood is open to discussion. Nevertheless in 2005 the Asthma UK audit of asthma (available online) revealed that in adults there was an increase of 400,000 diagnosed with asthma from 2001. To put this into context this figure is greater than the population of Bristol.

Across the UK there is regional variation in both the incidence of asthma (Lung & Asthma Information Agency (LAIA) 2006 online) and asthma associated mortality (NAC 2004). Concurrently with the variation in asthma incidence and prevalence there also exists a disparity associated with geographical area and the frequency of hospital admissions due to asthma (Asthma UK 2007). Considering England by Strategic Health Authority (SHA), the South West has a lower than average rate of asthma associated hospital admissions between 86- 94², compared with the North West and North East which have a rate greater than 115 (Asthma UK 2007 [online]). This can be conceptualized further by the considering the statement that

“people in the North west of England are 65% more likely to need emergency hospital asthma treatment than those in the East of England” Asthma UK 2007 page 7 (online) available from: <http://www.asthma.org.uk/index.html> accessed [17th June 2010].

² standardized to account for regional differences between age and gender the overall average is taken to be 100.

Such regional differences are considered in part to be due to a number of factors such as social deprivation and ethnic differences. It is known that people of South Asian descent who have asthma are three times more likely to require hospital admission due to their asthma (Gilthorpe, Lay-Yee, Wilson 1998). Ease of access to health care is a factor to consider in explaining regional differences in asthma treatment but regional differences are not due to differences in the type and severity of asthma experienced (Asthma UK 2009a [online]). Instead arguments are presented to suggest that the primary reasons are due to quality of care provision. Those strategic health authorities that have Primary Care Trusts (PCTs) who provide asthma associated health care that meet quality performance indicators (Quality and Outcomes Framework), have a population register with significantly lower incidence of asthma associated hospital admissions (The Information Centre, Quality and Outcomes framework, April 2005 – March 2006).

Financial costs of caring for people with asthma are variable but are estimated to have been in the region of £889 million in 2001 (DH 2006). It costs 3.5 times more to care for a person who has an asthma attack compared with someone who has well controlled asthma (Asthma UK 2009a). In 2005 it is estimated that it cost £58.3 million to provide hospital care for the management of asthma (Asthma UK 2007). In 2009 Asthma UK estimated that 75% of all emergency asthma associated hospital admissions could be avoided, with appropriate routine and timely care. Thus this would be potentially freeing £43.7 million in the health service associated with the provision of asthma acute care to be redirected and used elsewhere.

In 2004, of the hospital admissions due to asthma, 42.5% were children under 15 years (Asthma UK 2007). Duration of stay for quarter of these admissions is often less than one day, but 50% require stays between 3

and 7 days (Asthma UK 2007). This thus results in significant absences from their school and societal role, as well as influencing their parents/carers ability to go to work when their children are unwell.

Despite improvements in the management and treatment of asthma in the last twenty years the number of deaths due to asthma has remained fairly static within the UK. In 2002 1,400 people died from asthma, (General Registrar's Office 2002). The lung and asthma information agency (LAIA, 2006) provide summary information that in 2006 the number of deaths in the UK due to asthma was 1,199; 40 of these deaths were children under the age of 15 years.

2:2.1 Summary of this section.

Asthma worldwide is thus a significant health care problem, within the UK it affects at least 1 in 10 children and is responsible for being the most common childhood long term health condition. There is regional variation across England in frequency of asthma associated hospital admission and asthma exacerbations. Possible reasons for this include social deprivation, ethnic variations in the population but the most likely cause is the variation in quality and provision of health care. Financial consequences of poor asthma control to the National Health Service are high but asthma does demand a higher price from individuals and is responsible for circa 1500 deaths per year. The literature review now follows as discussed in earlier pages, commencing with a brief overview considering what is asthma.

2:3.What is asthma?

Asthma is a chronic inflammatory disorder of the airways in which many cells and cellular elements play a role. The chronic inflammation is associated with airway hyperresponsiveness that leads to recurrent episodes of wheezing, breathlessness, chest tightness and coughing, particularly at night or early in the morning. These episodes are usually associated with widespread, but variable, airflow obstruction within the lung that is often reversible either spontaneously or with treatment.

(GINA 2009 page 18)

Both the British Thoracic Society/ SIGN asthma guidelines (BTS(2009) [online]) and the USA Bethesda- National Heart Lung and Blood Institute (2006) asthma guidelines have similar definitions of asthma. These focus around the existence of respiratory symptoms of wheezing, breathlessness, chest tightness and coughing which are variable, intermittent and usually respond to treatment and are thus reversible.

Asthma UK (2010) (online) on their world wide web site refer to asthma as a condition that [I paraphrase] affects the airways, which are small tubes that carry air in and out of the lungs. Many other similar web based information sites also refer to asthma in similar words, for example NHS choices web site use a multimedia video to illustrate how the bronchi (small tubes in the lungs) respond to allergens and produces the symptoms of asthma available at

<http://www.nhs.uk/conditions/asthma/Pages/Introduction.aspx> [online] [accessed 17th June 2010].

The consensus of opinion regardless of whether the information is aimed at health professional, researcher, person/ parents and carers of those with asthma is that asthma causes significant difficulties in breathing and respiration. It can thus cause signs and symptoms of wheezing,

breathlessness, chest tightness and coughing and an individual who has these will most likely be experiencing airway inflammation which limits air flow throughout the lungs.

Consequently, in severe cases asthma can cause death as a result of inadequate gas exchange occurring sufficient to meet the physiological and metabolic demands of the body (occurring as a result of difficulties in breathing due to airway hyperresponsiveness associated with asthma). However, in many cases asthma causes the symptoms listed above which are themselves burdensome and have significant sequelae but do not result in the death of the individual. The consensus regarding asthma is that it is defined by its symptoms which are mainly generated by its functional consequences of airway responsiveness. Thus asthma is a disease that is described rather than given a definition concerning its pathogenesis.

2:3.1 Aims of asthma management.

Accordingly, following the definition of asthma discussed, the aim of asthma management is to reduce and thus gain control of asthma associated symptoms. Today asthma management guidelines exist in many countries designed to help clinicians and all who work with and interact with people who have asthma to help with its management. Asthma management guidelines were first introduced in the UK and USA in 1991 to provide recommendations for the optimal control of asthma (National Institutes of Health 1991). In countries where guidelines have been implemented there has been a reduction in asthma severity (Yawn *et al.* 2006). However, there is still room for improvement (Bellamy & Fisher 2005).

Massie *et al.* (2004) found that there was a significant gap between current clinical management of paediatric asthma, and current clinical best practice as recommended by clinical guidelines. They and others suggested that ideally national and international guidelines should be adapted to local settings with local ownership of the recommendations in association with an organised implementation programme (Heffner *et al.* 2000).

2:3.2 UK Asthma guidelines.

In 2003 the British Thoracic Society (BTS) and Scottish Intercollegiate Guidelines Network (SIGN) introduced wide encompassing guidelines outlining how asthma should be managed and treated in both children and adults. These guidelines were produced following rigorous scrutiny of research evidence to justify health care decision making processes, and provide uniformity for asthma care across the UK. Previous BTS guidelines had existed for the treatment of asthma in the UK (BTS, 1991; BTS 1993; BTS 1997), but these were based more upon expert opinion rather than research evidence and SIGN ranking criteria.

Until 2003 the BTS guidelines failed to confront key issues in asthma, such as agreement concerning what is an acceptable age to diagnose asthma, what should be the first line treatment options in newly diagnosed asthmatics and where to place newer (over the last decade) pharmacological advancements in treatment options. The most recent BTS/SIGN guidelines (2009) [online] however, have utilised a comprehensive and rigorous research based approach to develop key statements concerning the management of asthma care in the UK, and are intended to play a pivotal role in the management of UK childhood asthma.

BTS/SIGN asthma guidelines (2009) [online] state that the aim of asthma management is control of the disease; control is defined as the absence of asthma symptoms. However, they acknowledge that those with asthma may have a different agenda, tempering their desire to control and eliminate their asthma associated symptoms, with the consequences or side effects of the medication and changes in life style that they are required to undertake.

2:3.3 Global asthma guidelines.

Similarly the USA asthma guidelines state that treatment with anti-asthma medication can eliminate or reduce the symptoms of asthma, but that for some, chronic and permanent changes in airways (known as asthma airway remodelling), can result in some permanency to their asthma symptoms, producing a chronicity associated with their asthma rather than the more usual acute, brief episodes of asthma symptoms (National Heart and Lung and Blood Institute – National Institutes of Health (USA) guidelines available [online]).

The National Asthma Council Australia (2010)[online] and the Canadian asthma guidelines (2010) [online] have a similar approach to the diagnosis and management of asthma. Thus the overview of asthma management globally as presented in the GINA (2007) guidelines is wherever possible to eliminate the symptoms of asthma, reduce acute exacerbations and the need for rescue medication and intervention. In some cases this might not be achievable but this relates to those people who develop airway remodelling and hyperresponsiveness that is not completely reversible with current anti-asthma medication. All the asthma guidelines reviewed indicate that those who have asthma should be able to manage their own disease, recognize when their asthma requires additional intervention and take responsibility for their own medication. This applies to children and

adults, with the very young gradually increasing in their responsibility for their disease management. The BTS/ SIGN (2009) asthma guidelines indicate that school aged children should generally be able to manage their own medication at school and require less assistance with their medication as they progress through primary school.

2:4.4 Section Summary.

Asthma is variable; its symptoms can be life threatening and limiting. However, for many (but not all) symptoms are controllable and can be eliminated completely as a consequence of taking anti asthma therapy and life style changes. Globally this is the consensus opinion of all the asthma guidelines reviewed, and the stance of the GINA (2007).

Clinically asthma management of school aged children follows the aims outlined above; children under five years of age are specifically identified within the British Thoracic Society/ SIGN asthma guidelines (2009) and in the GINA (2007) guidelines. However, the salient differences in focus in asthma management in children under five is concerned with diagnosis, intervention in respect to medication that is available for young children and the prognosis of asthma in the very young. The principles of asthma management in children under five years of age in the UK remains to gain control of the symptoms of asthma.

2:4 What policies and guidelines exist to help schools and school personnel in their management of children's asthma?

Within England the Department for Education (DfE) has yet to produce guidance upon the management of asthma in schools. Thus current guidance relating to asthma is that provided by the DfES (2005) and concerns how medication is managed, the “managing medicines in early years settings” (2005). This document suggests that a good framework for practice is that all schools, school local education authorities (LEAs), primary care trusts and families work together

“to develop policies to ensure that children requiring medicines receive the support they need” (page 2 DfES & DH 2005).

Key features of this document are:

- that all schools and local education authorities are responsible for developing a school specific policy regarding the management of asthma (and other chronic health conditions, for example diabetes, epilepsy). It is the responsibility of employers (local education authorities) to provide these that each school then adapts to meet their own needs;
- how these children are cared for in the school environment should be explicitly stated;
- access and storage of medication should be explicitly determined in each school;
- each child with chronic health needs should have a specific health care plan that enables all staff in school to identify and respond to the child's health needs, and clearly identifies responsibilities and

communication between parents/ carers, children, school staff, local education authorities and primary care trusts;

- children should be allowed and encouraged to take responsibility for their own management of their disease, including administering their own medication whenever possible even from early ages;
- All staff are expected to be aware of this policy, to understand how chronic conditions are treated and managed and to have a working knowledge of the major symptoms of these diseases.
- Furthermore, schools are expected to have a register of all children who have chronic health needs.

The DfE website (2010) [online] (and previous education departments) provides additional links to various organizations that can help schools and local education authorities in planning and delivery of chronic health policies. Such websites include Asthma UK who have a resource pack, 'managing medical conditions in school' which provides helpful insight into how asthma (and other chronic health conditions) should be managed in school.

Some local education authorities in England do have school asthma policies, for example Norfolk local education authority (2010) available [online]. But it would appear that from reviewing both the policy documents and local education authority websites (via the DCSF website, (now DfE) accessed 8th May 2010) there is significant regional variations with many local education authorities not providing schools with asthma policies. Thus within England there are significant regional differences between local education authorities regarding whether or not they have chronic health policies written for their schools. This would appear to result from the fact that the policy issued from the DfE or its predecessors is suggested guidance and not at the level of a legislative directive.

Other countries have adopted similar approaches to help in the management of asthma in school. The USA has the National Association of State Boards of Education (NASBE) (2005) asthma policy which is supported by the Centre for Disease Control (CDC). This is similar in its construct to that used within England and suggests that responsibility lies with each individual school which can modify their (NASBE) generic policy freely to suit their own needs. However, the USA does have States that have legislation in force to help children have access to their inhalers when in school, for example, Alabama (2010).

The addition of legislation within some States regarding access to medication has seen a number of developed initiatives regarding asthma management and school asthma policies. One of the most pro active of these is New York which has initiated a series of training programs and reviews regarding asthma management. A summary of this is “Asthma and the school environment in New York state” (2008).

Canada follows both the USA and England in its policies and approach to the management of school asthma. All suggest that asthma should be managed to maintain and improve children’s asthma, and allow children to manage their own disease in a school environment which doesn’t antagonize/ exacerbate their asthma and with school staff that are both supportive and knowledgeable about the disease.

There is relatively little information available concerning how European countries (other than the UK) are managing asthma in schools. The Brussels declaration (2006) summarises a summit meeting held in the European Parliament indicating ten key points that need to be addressed in order to reduce the morbidity in Europe associated with asthma. The European Lung Foundation (ELF) provides links to respective individual European member countries web sites which all indicate that asthma

affects children in schools. However, this does not then lead to detailed guidance available for school staff in the management of asthma.

Thus it would appear that within England, Canada and USA there is a consensus that children at school with asthma need to be identified and helped to manage their disease. Characteristics of a school environment that helps and supports children with asthma in these countries would be:

- a school environment that facilitates their (school children with asthma) decision making and supports their autonomy;
- removing or reducing factors that are known to exacerbate asthma;
- adopts an inclusive attitude towards those children with chronic disease;
- school personnel understand sufficiently about asthma and its management to facilitate this and recognize when additional intervention/ measures may be required;
- good communication occurs between children, parents/ carers, health care providers and education providers to maximise children's well being.

2:4i. Nota Bene.

Subsequently to the commencement of this research and thus substantially later than the identification of the research questions and initial review of the literature (but not the research data collection) a young schoolboy of 11 died as a result of a severe asthma attack.³ However, the public coroner's inquiry and then the resulting media attention occurred 16 months after the data collection period of this research ceased.

The coroner's inquiry into his death identified a significant number of contributing factors. These included the school staff failing to act when he became unwell in school, a delay in informing his parents and then as his

³ Sam Linton, year 7 pupil at Offerton High School Stockport.

condition deteriorated further not calling for emergency first aid from the ambulance service. In total there was a three hour delay before he received emergency asthma care. These factors according to the coroner's inquiry are believed to have contributed to the child's death shortly after admission to hospital⁴. This death occurred December 2007, although the coroner's inquiry was not heard until March 2010.

2:4.1 The influence of school on the management of chronic health conditions.

This section will outline the premise that school and schooling are important in the development of children into adults, and that the school environment influences how children manage their chronic health both positively and negatively. Schooling has a crucial role in childhood development (Barnes 2006). It is accepted that the schooling a child has will underpin their development throughout life (Tracey 2001). Asthma is a known chronic illness and Diderichsen *et al.* (2001) argue that the consequences of chronic illness could be profound if the experience affected the individual's education, future employment or earning power. Milton *et al.* (2004) undertook a systematic review to consider the social and economic consequences of childhood asthma across the life course. They found that asthma significantly influenced attendance at school but not necessarily school related academic achievement.

The school environment is expected to be fit for purpose; the purpose in this context is to provide a safe secure environment that promotes and develops children's participation and involvement in school activities (DSCF 2009) [online]. Consequently schools are expected to reduce environmental factors that exacerbate children's asthma, for example not

⁴ Reported 18th March 2010 (Inquiry findings made public at that time).

to have indoor furry classroom pets such as hamsters or guinea pigs, have no damp walls and no fungal growth in the class rooms.

Bener, Kamal and Shanks in the United Arab Emirates (2007) found that schools located in areas of high air pollution had significantly higher numbers of asthma associated illness, increasing fourfold the number of asthma associated days absent from school. Reindak and Oymar (2006) found that children who were educated in schools that were damp and with a high mould spores count, had pupils with a higher than average number of days absences due to asthma. Similar findings were found in the USA by Sahakian *et al.* (2008).

Some of the issues identified in the home environment are also known to be a problem in schools, for example carpets and soft furnishings can harbour dust mites which are known to exacerbate asthma (Shedd *et al.* 2007). Some aspects of central heating and air recycling are also known to trigger some asthma attacks (asthma UK (2010) [online]) and schools are expected to try and reduce their exacerbation of asthma by considering using heating systems that are known to reduce asthma allergens. However, it should be noted that this is a significant cost for many schools and not a practical approach.

Systems that operate within school also need to be navigated by children successfully. For example, the school system often poses several obstacles for children in managing their asthma, for instance the inability to access their inhalers, exclusion from physical activities and the presence of asthma triggers in the classroom. It is or has often been the school secretary who is designated as the person to manage asthma or control access to medications (Eisenberg 1993).

2:5 What do school staff know and how do they manage pupil's asthma?

Asthma is the most common chronic medical condition that school teachers worldwide will encounter (McGhan 2002, Hamm-Ellen 2004). School teachers' knowledge concerning the management of asthma has been examined and reviewed intermittently throughout the last twenty years. However, in the UK there is an apparent scarcity of research exploring teacher's knowledge concerning asthma in comparison with other countries (a total of seven relevant reports were found, in comparison with a total of 147 for the USA). The USA, Australia, Malaysia and Europe have reviewed teacher's knowledge regarding asthma management in school and their knowledge concerning asthma and its treatment. These reveal the following trends in teacher's knowledge that are not just limited to one country but appear to be applicable worldwide.

In Germany, Szcpanski, Brockmann and Friede (2001) investigated via a survey approach what school teachers knew about asthma and its treatment, and the management of children with asthma. They found that school teachers did not know how to recognize an asthma attack, they did not feel prepared to help children and did not have sufficient knowledge concerning how asthma is currently treated. This lack of knowledge is found similarly in teachers world wide, in Singapore (Bahri, Nur and Rahman 2003); Egypt (Gawwad and El-Herishi 2007); USA (Bruzzese *et al.* 2010); Australia (French and Carroll 1997) for example.

Within England there is some evidence to suggest that this is likely to be similar situation for teacher's knowledge regarding asthma. McWhiter *et al.* (2008) suggest that schools have responsibility to promote health and well being for their pupils, this includes effective management of asthma. Brigs, Doak and Meek (2002) surveyed physical education (P.E.)

teacher's knowledge of asthma and found that they were more aware of asthma and its management than fellow colleagues not primarily teaching P.E.

McCann (2002) found that in the South of England surveying prevalence of asthma in this region some teachers that knew about asthma and its management but many did not have sufficient knowledge to recognise signs and symptoms of asthma deteriorating. Ebbut, Carruthers and Barnes (1995) found that teachers in a seven primary schools had varying attitudes and knowledge concerning asthma and its management. Many of these teachers were not aware of the common signs and symptoms of asthma deteriorating, how to help children who were experiencing an asthma attack and when to seek advice and help. These reports tended to use surveys as their method of data collection. All indicated that school teachers didn't know how to recognize signs and symptoms of an asthma attack, how asthma was treated and how to help children manage their asthma in school. Exploring this finding in greater detail reveals that there is a difference between secondary school teachers and primary school teacher's knowledge.

Teachers of secondary school physical education (P.E.) tend to understand more about the management of asthma than teachers of other subjects in secondary schools and also primary school teachers (Briggs, Christopher, Meek 2002; Ebutt, Carruthers, Barnes 1995). However, knowledge and understanding regarding asthma in physical education (main teaching subject/ focus of educational interest) teachers is still fairly limited. Stohlhofer *et al.* (1998) reported that only 34% of teachers knew that playing games in cold wind may provoke an asthma attack. Madsen, Storm, Johansen (1992) more positively found that 57% of their school teachers (Danish) knew that wheezing after physical exertion can be seen as an indicator of asthma, but then temper this with findings that 33%

knew exertion in cold weather can exacerbate asthma. However, these reports above adopted a survey approach, with relatively low response rates (ranging from 20-45%) asking school staff to agree and disagree with key statements. This type of method of data collection inherently reduces response rate and does not allow for greater exploration of the results.

French and Carroll (1997) also utilized a survey approach and questioned 134 school teachers in Australia concerning knowledge of child asthma management. They found that though their population were active in assisting children in the management of their asthma on a regular basis, they were not confident of having the knowledge on which to base their actions. The majority of their population stated that they didn't know how medication worked and how it should be used. Brookes and Jones (1992) used the same survey in the UK and found similar results in UK school teachers. However, both these papers found that those school staff that taught in secondary schools and were responsible for physical education programmes knew or scored better than other school staff.

Bevis and Taylor (1990) who developed the survey tool used by French and Carroll, and Brookes and Jones referred to above found that the majority of school staff did not know how, what, when or why medication should be given to children with asthma. Furthermore, they found that school staff either excluded children from school activities if they had asthma, or else allowed them to participate if they (children) did not usually need to take their medication during the activity. In one study of secondary school physical education teachers 60% of children with asthma were encouraged to participate in sport activities (Harris 2002). However, reviewing inclusion of children with asthma into school activities in primary schools indicated that school staff are less likely to include these children (Janz *et al.* 1993).

In Dublin a survey of school staff knowledge and experience of asthma management in school revealed similar information. Many school staff were not aware of the common signs and symptoms of asthma exacerbation in school aged children, how to manage their asthma, and when to become concerned (Hussey *et al.* 1999). Hussey *et al.* (1999) further revealed that school staff scored comparatively better on recognising the signs and symptoms of asthma than upon the management of the disease and knowledge of medication. However, Hussey *et al.*'s work indicated that teacher's knowledge of signs and symptoms was at best satisfactory and that knowledge re medications was poor.

It is reasonable to suggest that if individual's had asthma or knew personally someone who had asthma they might be more knowledgeable. Bell *et al.*'s work (2000) indicated that in the USA primary school teacher's knowledge of symptoms associated with asthma was greater if they had prior personal experience with asthma, or they themselves had asthma. However, this study only involved 28 staff, who had either severe asthma themselves or had a close family member with severe asthma. Severe asthma in this research is classified as that requiring significant anti-asthma medication (equivalent to the BTS/SIGN asthma treatment step four) and exacerbations requiring hospital admission in the year preceding Bell's data collection and inclusion into the research. Personal experience of this severity of asthma (which will have limited involvement in daily life), according to USA and UK asthma management guidelines would have dictated significant patient centred education regarding asthma management. This would readily be transferable to the management of pupil asthma.

Some European school staff underestimate the impact of asthma upon children's sense of self esteem and engagement within school and

academic achievement (Lowenthal and Lowenthal 1995, Austin *et al.* 1998). Similarly Finnish school staff consider that asthma does not play an important factor in children's development of friendship and peer support (Olson *et al.* 2004). In Australia, Zincone and Mohay (1988) discovered that school teaching staff were unaware that asthma could be associated with a reduction in educational achievement experienced by asthmatic children. Hamm (2004) explored how 42 teachers managed asthma in USA schools, and found that the majority of their staff were not aware of those children in their class that had asthma or how to manage asthma should it become a problem.

This lack of knowledge and understanding that some school teachers have worldwide concerning asthma and how it is managed in school is not suggested to be due to lack of interest by school staff (McWhirter *et al.* 2008). Rather it is a consequence of school staff 'business' in delivering other requirements associated with teaching (Lim, Wood, Cheah 2009). Some papers and reports exist that are aimed to provide information regarding how to manage asthma in school Frieman and Settel (1994), Peterson *et al.* (2010), but these do not appear effective in changing knowledge and practice. This is despite the influence of educational directives and government strategies to develop school asthma policies existing world wide as discussed in previous sections.

School teachers are not aware of the common signs and symptoms of asthma and failed to recognise it in a number of their pupils is discussed above. This remains substantiated in more recent years for example see Wildeharbour *et al.* (2006). Furthermore, they have poor knowledge concerning asthma medications, purpose of inhalers and asthma management *per se* (Hussey *et al.* 1999, Snow *et al.* 2005). School staff are often unaware of whose responsibility it is to administer, deliver and

report medication use and communicate this to children and parents/ carers (Snow *et al.* 2005, Olson *et al.* 2004, Stieler 1994).

This review of teacher's knowledge represents a 'snap shot' of the global picture concerning teacher's knowledge and attitudes concerning asthma management in schools. Reasons why school teachers may not be able to give asthma their best attention, or are 'asthma un-aware' are likely to be varied and multi-factorial; for example this may be in part due to the increasing demands placed upon school staff time regarding educational policies and delivering curriculum focussed education (MacBeath and Galton 2008). Other suggestions are based that in teacher training programmes first aid and the management of common chronic conditions should be addressed (Hussey 1999, Delgado 1999). However, some English teacher training programmes do address the issues of common child ill health conditions but not all (DCSF 2009 [online] review of teacher training programmes validated by DCSF in England 2009, conducted by the author).

Other methods are suggested for improving teacher's knowledge concerning asthma. These involve teacher led educational programmes, linking health professionals and educators in their delivery (Sapien, Fullerton-Gleason, Allen 2004). However, such programmes do not always lead to sustained change in knowledge and practice of educators (Hazell *et al.* 1995, Bushby 1997, Bell *et al.* 2000, McWhirter *et al.* 2008). Other methods suggest that school educators/ teachers need to be participatory in their programmes of education regarding the management of chronic health conditions in school (Henry *et al.* 2004). For example Getch and Neuharth-Pritchett (2007) created a tool that helped teachers identify gaps in their knowledge concerning asthma, and suggested methods of rectifying these. Sapien, Fullerton-Gleason, Allen (2004) demonstrated that it is possible for school teachers to recognize respiratory distress in

children and that this method of teaching was enhanced with the use of video footage rather than just didactic information.

It remains to be evaluated further whether or not these later models would consistently improve school staff knowledge regarding asthma management in school. However, the literature indicates that school teaching staff are often unaware of:

- the common signs, symptoms of asthma;
- how common medication works;
- what school based activities they can expect children with asthma to participate in;
- frequently underestimating the impact of asthma upon children's development and school based interactions, and academic achievement within school.

There is limited information available regarding school personnel's knowledge of asthma and asthma management whom are not designated teachers, for example school meal assistants, classroom assistants. The exception to this is designated school first aid staff, who are expected to have undergone statutory education regarding the management of asthma in school and have regular updates information available (DfE 2010)[online]. However, no research evidence is available to substantiate this expectation.

Consequently there is some suggested evidence that teachers have poor, limited knowledge concerning asthma and its management in schools. Schools are keen to provide optimum care for pupils, but that at times optimum care is not always available in respect to the management of pupil asthma. We do not know what the experiences of asthma management of school support staff are, or their attitudes and knowledge

apart from the suggested minimum knowledge required for the role of a designated school first aiders.

2:6 Prevalence of asthma symptoms, what are the effects of asthma symptoms upon children?

Several international surveys have demonstrated that patients with asthma are accepting a high level of daily asthma symptoms (Bellamy & Harris 2005). The Asthma Insights and Reality in Europe study (AIRE) (Rabe *et al.* 2004) found that over half of 2,800 patients reported asthma related daytime symptoms and a third reported asthma related sleep disturbances. In children in England the asthma associated morbidity is harder to quantify, but evidence from these and other studies indicate that children with asthma expect not to be able to participate in daily school activities (Salisbury *et al.* (2002) and Francis (2001)).

In other countries more is known about the effects of asthma upon childhood. Fuhlbigge *et al.* (2006), found that the goals of asthma management and prevention of symptoms have not been achieved for the majority of children in Europe. Furthermore, they state that the impact of asthma on children's daily activities is substantial; 47% avoid exertion and 43% stay inside to improve control of their asthma symptoms. Children with asthma do not frequently participate in sport activities (van Gent *et al.* 2008). The majority of children, 78% in Rabe *et al.*'s (2000) research, report that the worst thing about their asthma is their inability to participate in sports. Similarly the AIRE study (2005) shows that 29.5% of children have limitations with sports. However, other authors have indicated that there are no differences in physical activity between children with undiagnosed asthma, diagnosed asthma and healthy control subjects (van Gent *et al.* 2007). The differences between these findings are perhaps due

to differences between methodologies, diagnosis in asthma and asthma severity.

2:6.1 Impact of asthma upon social functioning.

A main goal of asthma treatment is to enable children to feel and function normally in their daily lives (GINA 2009). Social function is frequently divided into impact upon individual and upon family social interactions. Children with asthma find that they can have reduced contact with friends, school participation and study activities (van Gent *et al.* 2008). This does not seem to be dependent upon severity of asthma, even those with mild asthma can feel socially isolated (Usherwood *et al.* 1990, Townsend *et al.* 1991, Nocon 1991, Christie *et al.* 1993, Gentile 2008).

Some reasons could be due to non or limited participation in sports, which are known ways of socializing with peers and help improve self confidence (Oseid 1982, Bussing *et al.* 1995). It could be postulated that reduced physical activity leads to increased psychological and emotional problems in children (Butz *et al.* 1995). This occurs as a consequence of decreased physiological tolerance to exercise, lowered levels of circulating adrenocorticosteroids (which are associated with enhanced mood and feeling of wellbeing, enhanced secretion occurs during exercise) and the associated isolation from peers who are participating in physical activities. Roder *et al.* (2003) found in the Netherlands that children with asthma have a significant lower participation in sports and lower self esteem than their non asthmatic peers. However, only Perrin *et al.* (1992) have conducted trials to investigate if psychological functioning of children with asthma is improved with stress management and education initiatives. Yet to date there is no consensus regarding how best to assess psychological well

being and adaptation in children with asthma, and asking parents alone is known to have inherent methodological problems. Parents are known to underestimate the impact of asthma upon children's well being (AIRE 2005, Juniper *et al.* 1996a, 1996b).

Social isolation and well being influences not just children with asthma but also the family (Celano & Geller 1993). Miller and Wood (1991) propose a model for how family dynamics are altered with the diagnosis of a child with asthma. This can result in some families becoming isolated, or adopting coping mechanisms that influence friendships and children's development of strategies to their self management of asthma.

The effects of asthma upon schooling in the USA are discussed below. Mannino *et al.* (2002) state that 14 million school absence days are lost due to asthma with on average 10 days lost from school per child with asthma. Newacheck and Halfon (2000) state that this is twice the number due to other child chronic health conditions. Van Gent *et al.* (2008) suggest that absences from school, restrictions upon school activities and social isolation from peers lead to significant impact upon children's schooling. Short absences from school can influence academic attainment (van Gent *et al.* 2008), sleep disruption and daytime tiredness affects cognitive functioning and mental ability. Children from lower socioeconomic families and urban areas are more likely to have greater deleterious effects upon their well being associated from asthma (Monalto *et al.* 2004, Warman, Silver and Wood 2009). According to asthma guidelines children with asthma should be able to attend school just as 'healthy' children do (van Gent 2008, BTS/SIGN 2009, GINA 2009), with little or no asthma associated school absences and participate fully in school life.

2:6.2 What do children feel about their asthma?

Butz and Alexander (1993) suggest that children with asthma who have had an asthma attack feel very anxious about the possibility of having another one. Children who are anxious can exacerbate their asthma, provoking an asthma attack and there is a known link between emotional state and asthma (BTS/SIGN 2009).

Asking children about their asthma, how they feel about it and strategies that they use to manage their asthma does not appear to be a popular methodology undertaken by researchers. Trollvik *et al.* (2010) conducted a small research study with 15 children asking the children to discuss their pictures and drawings that they had created examining what it was like to live with asthma. This found similar themes to those explored (2.6.1) in the literature.

However, some research has been undertaken assessing children's asthma associated quality of life. Quality of Life (QoL) is a term used to gain a measure of how individual's feel they are experiencing their life, Bowling (2005) states that it is a measure of how good life is. In health care it is usually associated with how people who have a chronic disease live and perceive their life and their activities in context with that chronic disease. Thus if their chronic disease/ condition is not affecting any of these factors they will have a good quality of life. This concept is substantially discussed later in this thesis (please see chapter seven). However, a summary of the key principles of QoL are listed here to allow appreciation of the following papers.

Health related quality of life (HRQoL) is used in health care to assess how a change in health status is affecting individuals in respect to their participation and enjoyment of their life (Bowling 2005). It is a subjective

evaluation and asks for respondent's perception of how they consider their life is affected by their health condition. In the context of asthma, a disease that affects breathing, sleeping and participation in activities and attendance at school evaluating HRQoL requires detailed consideration. Several child disease specific tools (questionnaires) for the assessment of asthma associated HRQoL have been developed. These include Juniper *et al.* (1996a) and French *et al.* (1994) which have been used widely in the assessment of the child's perceived effects of asthma upon their quality of life. Criticisms have been raised concerning whether or not children can complete these questionnaires reliably, but it appears that children with an age appropriate questionnaire (both Juniper and French have between them adapted their questionnaires for children aged five- 17 years), can complete these questionnaires appropriately and reliably (Yoos *et al.* 2003, Williams and Williams 2003). Sawyer *et al.* (2001), Guyatt *et al.* (1997) state that children are able to assess and respond appropriately to questions associated with quality of life. Yoos *et al.* (2003) provide evidence that children as young as six can reliably associate asthma symptoms with consequences and limitations upon activities, recalling them over several days. Responses are more likely to be representative of their reality if undertaken away from parents and carers (Tai *et al.* 2009, Juniper *et al.* 1996a, 1996b, 2008).

Sawyer *et al.* (2001) assessed asthmatic children's quality of life and how this influenced family functioning. They found that asthma significantly influenced how the family function as a direct result of a reduction in children's quality of life. Quality of life is affected by chronic asthma. This affect of asthma upon quality of life is still supported by a more recent study conducted in the USA using the internet and a validated HRQoL questionnaire, which found that children with asthma are still experiencing significant impairment upon their quality of life as a consequence of uncontrolled asthma (Dean *et al.* 2010).

Warschburger *et al.* (2004) found that it was possible to improve health related quality of life in children with asthma following a specific educational intervention programme. Others such as Monalto *et al.* (2004), Cujipers *et al.* (1994), Juniper *et al.* (1996a), French *et al.* (1994) all find that asthma affects children's quality of life. Le Coq *et al.* (2000) Schulz *et al.* (1994), Halterman *et al.* (2004), also found that asthma affects parents and families quality of life.

The majority of research presented above has been conducted outside the UK and England. It is not known if these thoughts and experiences are shared by English school children. Only one research report adopting a participatory method of data collection, published upon the internet but not cited in academic journals reports that children in two schools who have asthma feel isolated, frustrated and not supported by school staff (OPSR 2004). Discussing these findings further with the author of the report reveals that this report relates to children aged 10 -14 and is from two diverse schools one a primary school and one a secondary school, in two different socioeconomic and geographical locations.

In summary, asthma affects both children with asthma and their families. This can be explored using quality of life measures, surveying days absent from school and participation in daily activities as well as qualitative methods of enquiry. Many children with asthma adopt coping mechanisms that they develop with time to help manage their asthma and reduce their symptoms. Asthma and its symptoms can affect children's participation in school based activities and interactions with peers. Some children with asthma have reduced attention and engagement in school and this influences their attainment in education. Much of this work has been undertaken in countries other than England and how asthma influences young children at school in England is not yet explored.

2:6.3 Summary of literature review and development of the research questions.

The remaining sections will conclude and synthesize all the presented literature and demonstrate how the research questions were derived from the evaluation of the literature reviewed above.

Asthma is a significant global burden and it is the most common chronic childhood disease in the UK. Guidelines exist for how asthma should be managed; these represent best practice and consensus opinion. Guidelines exist both with a global focus and also some are country specific. The aims of all asthma guidelines are to reduce symptoms of asthma such that those with asthma have no restriction upon their daily life activities.

Many children with asthma experience high levels of asthma associated morbidity. Many children find that these symptoms significantly reduce their engagement in school and achievement in school system. Furthermore, asthmatic children can feel socially isolated and develop psychological illnesses.

School is a substantial influence upon children's sense of development and well being. Some social isolation exists in school for asthmatic children. School staff are expected to act in *loci parentis* and promote children's well being and self management of asthma. However, many schools have school staff that do not appear to know about asthma, how it is treated and managed and how to recognize the signs of an asthma attack.

Nonetheless, often the research précised above has been conducted in countries other than the UK, in many cases upon children in secondary education and not primary schooling. Using survey approaches to gather

their data. It is not known if this is the experience of children with asthma in England. Consequently the following research questions have been generated in order to explore the gaps in the literature presented above and relate the research conducted in other countries to England.

It is not understood what happens to children with respect to their asthma when they attend English early years schooling in which they are:

- expected to start to manage their own asthma;
- to take responsibility for their own medication;
- to avoid their asthma triggers;
- to participate in all school activities;
- to articulate need for reliever medication;
- likely to miss school due to asthma exacerbations;
- without a parent/ carer to express their asthma related needs in the school environment;
- making friends who may not have asthma.

Exploration of these issues will provide an understanding of what factors need to be considered when empowering children to manage their own asthma. This would help development of local (school related guidelines) for managing asthma as suggested by Heffner *et al.* (2000).

Understanding these issues will help reduce situational barriers that children have to overcome, such as the location of medications, the construct of school policies for example and also address issues around school personnel education and understanding of the disease.

3: Methodology

This chapter discusses the choice of research methods, including a consideration of their associated theoretical issues and then presents the design of the research and its practical organization. The chapter commences with the research aims and questions and then explains how the adopted ontological and epistemological stance provides a link between the aims and the practical methodological issues of data collection. An examination and discussion of the sample selection process used for data collection and how the data has been analyzed is considered. Furthermore, the evaluation and reflection upon the ethical issues inherent within the research design, and the practical strategies undertaken to ensure that the research complies with and also maintains essential ethical principles are discussed. A review of the anticipated strengths and weaknesses of the research design is presented. This schema is based upon that suggested by Clough and Nutbrown (2002) who consider that the methodology should provide logical structure and address these issues in particular.

3:1 Principal aims of this research:

- to explore, describe and characterize the school related experiences of asthma and its management as perceived by asthmatic primary school pupils in their school setting;
- to explore, describe and characterize the school related experiences of asthma management and thoughts of primary school staff;

- to consider the variations that exist in asthma experiences (of both children and staff) and the management between schools and the factors that may influence these.

These aims are then further conceptualized in the form of the following research questions. The overarching research question is:

- what and how is asthma experienced and managed in primary schools?

This can then be broken down into the following five research questions:

- What are children's experiences of asthma within primary schooling? (Qualitative and quantitative methods are used).
- What are the experiences of teachers and school support workers concerning their involvement with child asthma management? (Qualitative methods are used).
- What policies do schools have in place concerning the management of child asthma? (Quantitative methods are used).
- How do these policies compare with National Asthma Guidelines? (Quantitative methods are used).
- Are there differences between schools concerning their asthma management? (Synthesis of the research findings to occur in order to answer this question, blending the findings and data as required in a mixed methods study).

3:1.1. Methodological issues arising from these research questions.

In order to address the overarching research question both qualitative and quantitative methods of enquiry are required. The combining of these methods is the initial premise for the use of a mixed methods approach as argued by Teddlie and Tashakkori (2009). The use of a mixed methods framework will be discussed throughout this methodology and considered further in section 3.3.

In view of both the research aims and research questions thought had to be given to some of the key methodological issues that needed to be addressed. These issues required the use of an ontological view point that would allow combining of methods of enquiry and blending of research findings sufficiently to answer the research questions. This combining of both approaches has become in recent years more common within health and social care research (Pope, Mays and Popay 2007). However, the use of two disparate methods of enquiry requires careful consideration and a robust framework for its use (Plano Clark and Creswell 2008). This combining of both qualitative and quantitative methods is known as 'mixed methods' research and will be discussed more fully later in this chapter (section 3:3).

It is important to provide information relating to the assumptions and beliefs of the researcher in this thesis. This is suggested by Crotty (1998) as a key requirement of the methodological chapter of a thesis. All research begins with certain assumptions held by the researcher (Cresswell *et al.* 2004), these have various names ascribed to them depending upon which belief system is adopted and which research tenets are held. For example they are referred to as paradigms by Lincoln & Guba, (2005); philosophical assumptions, epistemologies and

ontologies by many including Crotty (1998), or broadly conceived research methodologies (Neuman 2000). Deliberation of these assumptions is inherent within the choice of research methods since beliefs held by the researcher influence the research process both implicitly and explicitly (Oliver 2008).

The first consideration is what ontological viewpoint the researcher and thus the research enquiry itself is placed within. The ontological view point dictates what is held to be 'knowledge and truth' and thus what it is possible to discover and consider in this research. Consequently, in this research the ontological approach required must allow the use of both qualitative and quantitative methods. The ontological theoretical framework adopted throughout this thesis is that of a pragmatist and will be discussed more fully in section 3.2.

3:2 Pragmatism, the ontology utilized in this thesis.

Pragmatism derives from the late nineteenth century and notably the works of Peirce, James, Mead and Dewey set in the late 1880s (Cresswell 2003). More recently others have addressed and considered this belief system, for example Cherryholmes (1992). Pragmatists believe that knowledge claims arise out of actions, situations and consequences rather than antecedent conditions. There is an emphasis upon applications with "what works" and solutions to problems (Patton 1990). Instead of the research methods being most important it is the problem that is central and researchers use all approaches to understand the problem (Cresswell *et al.* 2004). Tashakkori and Teddlie (1998) and Patton (1990) in social science research, convey the importance of focusing attention on the research problem and then using pluralistic approaches to derive knowledge about the problem.

Pragmatism provides a basis for the following knowledge claims:

- Pragmatism is not committed to any one system of philosophy and reality. This allows application to mixed methods research in that the enquiry draws liberally from both quantitative and qualitative assumptions when engaging in research (Teddlie and Tashakkori 2009).
- Individual researchers have a freedom of choice. They are free to choose the methods, techniques and procedures of research that best meets their study's needs and purposes (Ritchie and Lewis 2003).
- Pragmatists do not see the world as an absolute unity, believing that the world will reveal different findings against the same question depending upon the method of enquiry. Similarly, mixed methods researchers look to many approaches when collecting and analyzing data rather than subscribing to only one (Bergman 2008).
- Truth is what works at the time: it is not based in a strict dualism between mind and reality completely independent of the mind. This premise allows the adoption of mixed methods research, using both qualitative and quantitative data because they work to provide the best understanding of a research problem (Pope, Mays and Popay 2007).
- Pragmatists agree that research always occurs in social, historical, political and other contexts (Greene 2007).

Pragmatism as a belief system allows the use of both qualitative and quantitative methods of enquiry within the same research study. This combining of what are often considered disparate approaches (Polit and Beck 2006, Parahoo 2008) within the same enquiry requires an

ontological view point that does not denigrate the significance or value of any research findings.

Thus the consideration of pragmatism as the ontological viewpoint adopted in this research is made resulting from the deliberation upon the points discussed above. This belief system leads to the consideration and support of mixed methods as the choice of methodology suitable for the enquiry into this research topic. This will be discussed further in section 3:3.

At this stage in the methodology chapter the arguments have been presented for the ontological viewpoint held by the researcher, that of pragmatism. The primary aims of this research has also been discussed (please also refer to the chapters one and two). The chapter now moves on to discuss methodological detail associated with qualitative and quantitative research and the generation of a mixed methods approach to this research.

3:3 The use of a mixed methods theoretical framework – (a summary argument for choice of the research design frame work).

The ontology of pragmatism opens the door to multiple methods, different worldviews, and different assumptions as well as to different forms of data collection and analysis used in a mixed methods study. Thus considering the chosen ontology of pragmatism the choice of methods for data collection is not rigidly defined. Consequently the development, consideration and design of a mixed methods framework for data collection and analysis arose as argued below. Discussion also addresses the purpose and rationale for the reasons why quantitative and qualitative research methods need to be mixed in the first place.

The choice of research methods is dependent upon many factors and questions that should be considered in the initial research proposal. Cresswell (2003) suggests that these questions can be considered conceptually as in Figure 1.

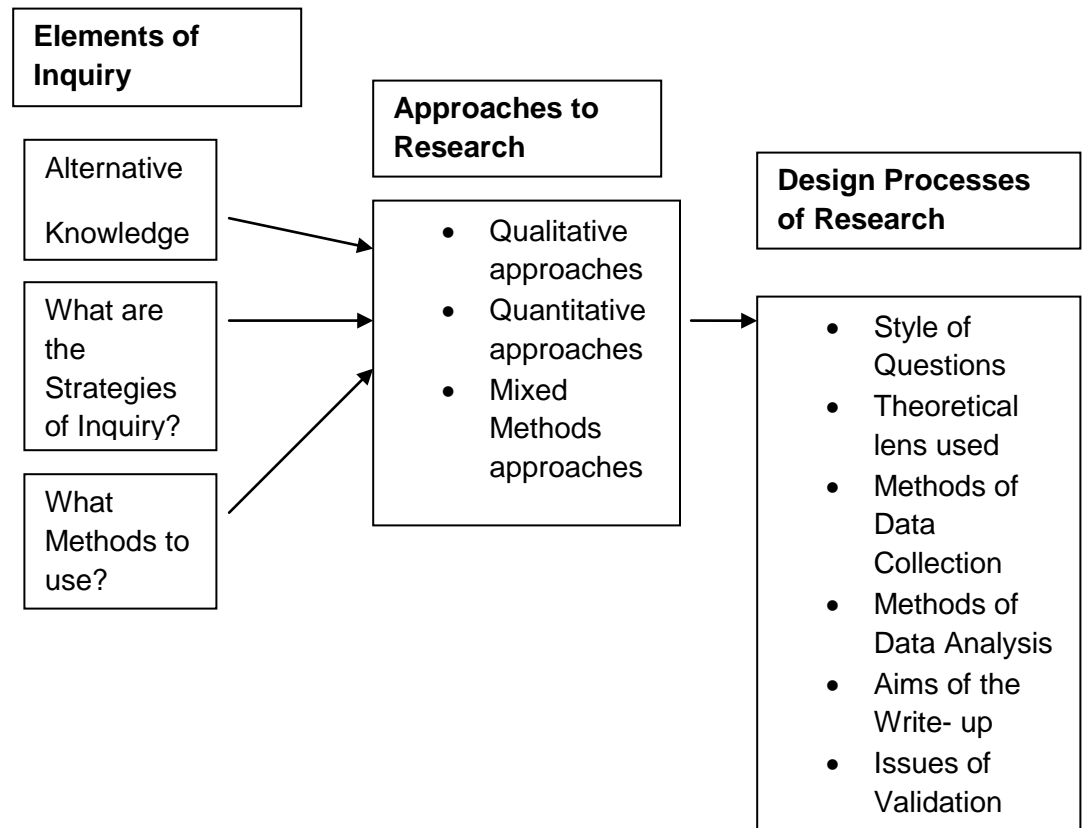


Figure 1: Research Process Design.

Knowledge claims, strategies of inquiry and methods leading to approaches and the design of the research process (adapted from Cresswell 2003).

Reviewing Figure 1 it can be seen that the requirements of the research can drive the methods and design of the research inquiry. *Id est* research that needs to be replicated by others and provide evidence that there is a direct link between cause and effect directs the world view and theoretical lens to be that of a quantitative approach. This then directly informs the methods of data collection, strategies of inquiry and claims about knowledge and what is truth. Conversely the interest in exploring a phenomenon, which may be perceived by people in differing contexts, using various and multiple belief systems that does not need to be replicated by others but describes a situation observed by the researcher in a defined context leads to the use of qualitative methods of inquiry.

The following paragraphs present a discussion of the issues and the argument that the aims of this research dictate that the research framework should include in its design aspects of both qualitative and quantitative methods of data collection (Teddlie and Tashakkori 2009). This is known as a mixed methods approach (Plano Clark and Creswell 2008).

Mixed methods research questions, according to Teddlie and Tashakkori (2009) are concerned with unknown aspects of a phenomenon. They are answered with information that is both in narrative and numerical forms, requiring at least two research questions one being qualitative in focus and one being quantitative in focus. This is considered the unique asset and benefit of mixed methods. In the context of this research the unknown aspects of asthma in school generated both qualitative and quantitative questions and thus drove the choice and use of mixed methods to explore and answer the research questions.

The aims and benefits of mixed methods according to Bergman (2008) can be considered simply as taking the best of qualitative and

quantitative methods to combine them in order to answer the research question. In contrast Denzin and Lincoln (2005) criticize the use of mixed methods stating that there is still a hierarchical approach to the use of both qualitative and quantitative methods, with quantitative methods achieving the majoritive focus and qualitative methods being seen as rather auxiliary. They also added that mixed methods takes qualitative “methods out of their natural home, which is within the critical, interpretive framework” (Denzin and Lincoln 2005 p 10). However, Teddlie and Tashakkori (2007) provide evidence to counteract this referring back to the origins of mixed methods in which both qualitative and quantitative methods are given equal priority (for example see Brewer and Hunter 1989). Recently Cresswell and Plano- Clark 2007 have argued against using qualitative work as exploratory and quantitative methods as confirmatory in construction of mixed methods framework. Mixed method researchers assert that there is no ‘natural home’ for any research method, stating that the mixed methods perspective is that multiple frameworks or paradigms can be associated with any given method (Teddlie and Tashakkori 2007). Interestingly Denzin and Lincoln (2003) assert in another paper that qualitative methods are associated with a wide variety of different philosophical orientations other than just those listed as the ‘critical interpretative framework’ in their 2005a paper.

However, Bergman (2008) urges caution in merely using this idea of combining the best of both qualitative and quantitative methods as the justification for combining these approaches stating that the methodological issues associated with compatibility cannot be ignored. Bergman argues that a consideration of the issues surrounding both approaches should be presented and the way mixed methods will be integrated throughout the research should be explicitly described. These

are discussed in the context of this research in the subsequent paragraphs.

Qualitative research's main strength is its ability to study phenomena from the perspective of those experiencing the phenomena (Silverman 2004). It is considered that one real strength of qualitative research is that it can use naturally occurring data to find the sequences ('how') in which participants' meanings ('what') are deployed and thereby establish the character of a phenomenon. Marvasti (2004) states that one of the benefits of qualitative research's aims is to provide

"Detailed descriptions and analysis of the quality or substance of the human experience"

(Marvasti 2004 page 87 chapter in *Doing Qualitative Research: a comprehensive guide*, Silverman D, Marvasti, A.)

Qualitative research provides detailed accounts, recognizing and explaining social context and discussing ambiguities. Thus qualitative research will allow contextual sensitivity, i.e. how the phenomenon is actually put together by its participants (Silverman 2006). In this case the 'hows' are how school staff working with children and children with asthma think, perceive, manage and understand their asthma (phenomenon) in their school setting (context). This is summarized further in Figure 2

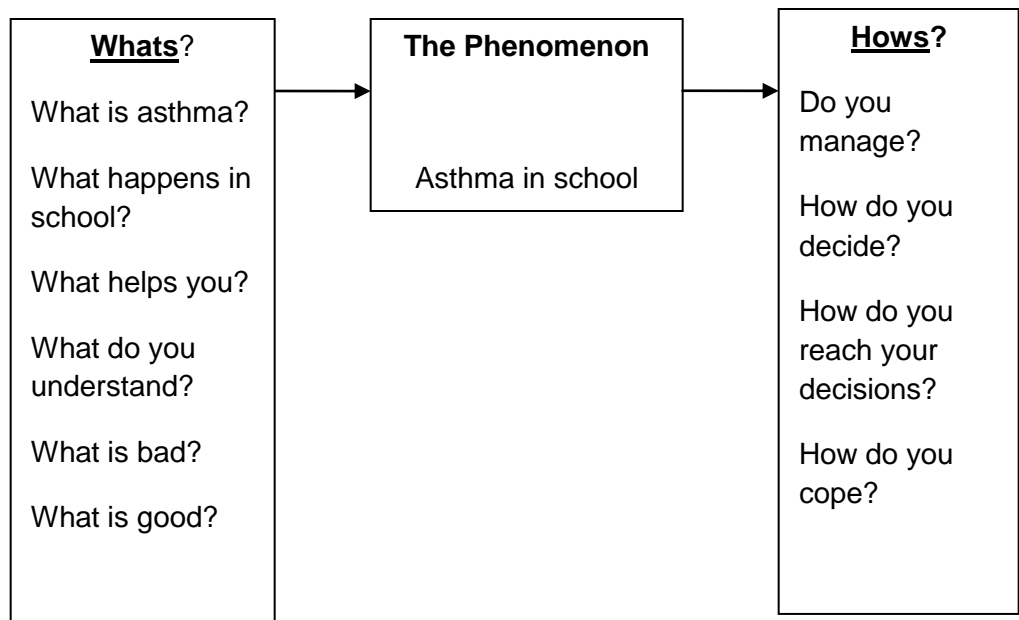


Figure 2: Benefits of qualitative research approaches.

Figure 2 is created by applying to this research enquiry Silverman’s (2006) notation concerning the type of questions that qualitative approaches are often used to answer, and elucidate how a particular situation or context influences the research subjects. This consideration of the properties of qualitative methods provided the evidence and impetus for the adoption of qualitative methods of data collection in this research. Without the use of qualitative methods it would be impossible to gain an understanding of the school environment (contextual sensitivity), or how children and school staff think about their asthma in the school day, what they do to manage their asthma or even if they do manage their asthma within a school setting. Thus addressing the

research aims: what are the school related asthma experiences of both children and staff, required a qualitative approach to be adopted. However, this method alone was insufficient to answer all the research questions in this thesis. Thus the concurrent consideration of quantitative research methodology provided the evidence for utilizing this approach combined with qualitative methodology to address the research questions.

Quantitative research is concerned with establishing correlations between variables, with the phenomenon under study having ascribed to it an 'operational' definition of the phenomenon (Ritchie and Lewis 2003) As a result the contribution of quantitative research to social problems is likely to be limited (Silverman 2006). Denzin (1989) further articulates this property of quantitative methods (in the context of criticism, but none the less correctly) stating that it assumes that what is being studied is external to the observer, does not change over time and is not influenced by being observed.

Reality, truth and facts are viewed as existing externally to the researcher. Quantitative research searches for universal explanations for phenomena (Smith and Glass 1987). Explanation of findings in quantitative research emphasizes the quantification of outcomes and how this could apply to the wider population and prediction. However, the contribution of quantitative research to scientific development, enquiry and human advancement is without dispute (Pope, Mays and Popay 2007). Regardless of the myriads of personal belief systems as to the relative value of using qualitative versus quantitative research methods in any research design, in this thesis the use of quantitative research methods is an essential requirement to answer some of the research questions.

The benefits of quantitative methods are essential characteristics required in addressing the specific research questions: what are the

differences between schools and what policies are in place to manage asthma and how do these compare to the National standards? Figure 3 illustrates the conceptual properties and research questions that were reflected upon in the selection of quantitative research methods. This is the relationship between cause and effect, *id est* what asthma policies do schools have, and do children and school staff know about and follow these policies?

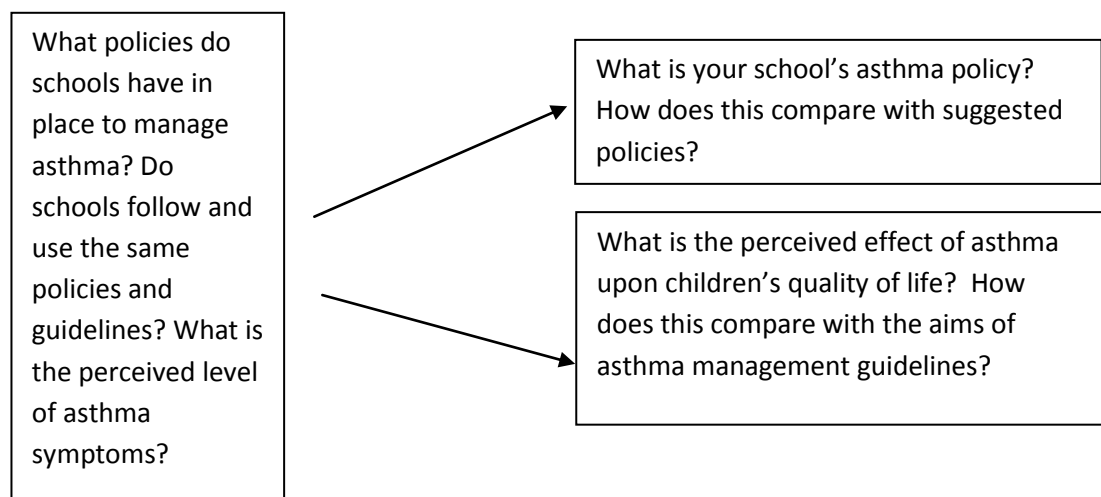


Figure 3: Quantitative methods, contextual consideration of the research questions.

An examination of the differences and similarities between schools involves gaining descriptive statistical data pertaining to each school and each research participant to allow comparison, analysis, report, categorization and consideration of this question. Similarly the research and analysis of school asthma policies required the use of surveys and content analysis.

3:4 Epistemological stance adopted and the value of mixed methods in this research enquiry.

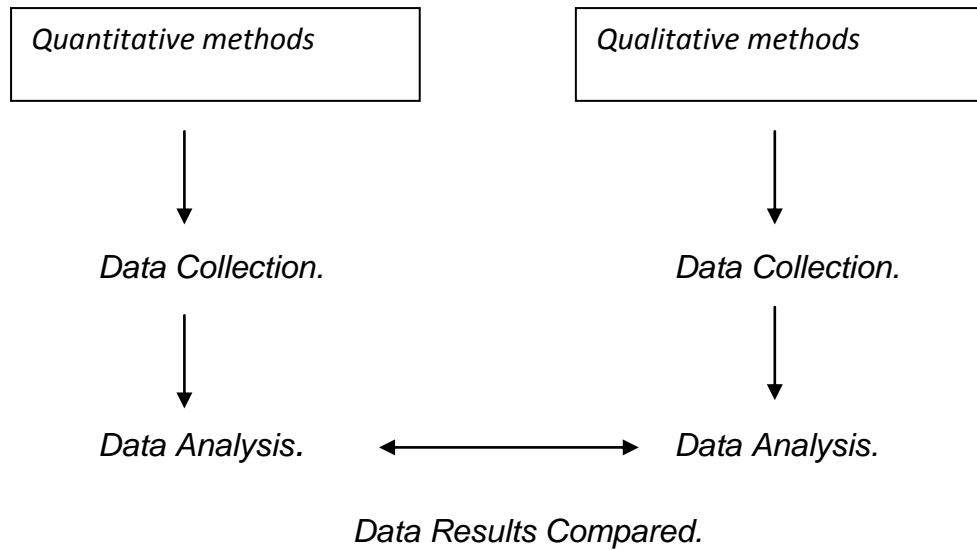
Utilizing a range of research methods and combining qualitative and quantitative research in the same project allows for a detailed and comprehensive enquiry (Hanson 2006). However, the use of multi-method research is not without its critics or problems (Blaikie 1993). Burgess (1993) states that the epistemological and ontological differences between qualitative and quantitative research will produce contradictions and ambiguities. However, this makes for a more challenging research process and requires a more sophisticated and informed methodology (Plano-Clark and Creswell 2008, Teddlie and Tashakkori 2009).

Debate continues about whether the two approaches can be successfully integrated into the same project or if they should be viewed as complementary but fundamentally separate approaches (Neuman 2000, Creswell 2003, Pope, Mays and Popey 2007). However, in this thesis the decision to actively use a mixed methods approach has been chosen and considered advantageous both in view of the ontology adopted and the research aims expressed.

Using mixed methods requires a clearly identified structure for how qualitative and quantitative methods are to be used and how the results are to be integrated (Teddlie and Tashakkori 2008). This then allows the reader to understand how the results are synthesized and inferred later in the research in order to provide a comprehensive answer to the research questions initially proposed.

For a study to be considered as that of 'mixed methods' integration of both qualitative and quantitative methods must occur at some phase of the research process (Tashakkori and Teddlie 1998, Greene *et al.* 1989, Teddlie and Tashakkori 2008). Integration is considered the stage of the research process at which both qualitative and quantitative approaches are presented together. In this research integration occurs at the conception of the research questions and follows then throughout the research in both the stages of data collection and subsequent analysis. It is then most apparent at the stage of interpretation of the results, or convergence (Cresswell 2003) of the findings.

The design of the research framework is a concurrent triangulation design (Teddlie and Tashakkori 2008). Triangulation in this context is that the phenomenon of managing asthma in school is the object of all methods of data collection and all results and findings relate to the same phenomenon. So 'triangulation' in this context is that all methods of enquiry allow greater understanding of the phenomenon and can be applied simultaneously to the phenomenon in order to exemplify it. Greene *et al.* 1989 and Morgan 1998 cite this as the most suitable design to use when a researcher uses two different methods in an attempt to confirm, cross validate or corroborate findings within a single study. Generally this design uses separate quantitative and qualitative methods as a means to offset the weaknesses inherent within one method with the strengths of the other method. Quantitative and qualitative methods of data collection are usually concurrent happening in one phase of the research study, with equal weighting given to both methods. This design usually integrates the results of the two methods during the interpretation phase; please see Figure 4 below which illustrates the principles of concurrent triangulation design.



Adapted from Teddlie and Tashkorri (2008) key principles of a concurrent triangulation design used in a mixed methods research framework.

Figure 4: Key principles of concurrent triangulation.

The use of mixed methods as the framework allowed the research design to unfurl as outlined below in sections 3.5 and 3.6. The research framework illustrates the key stages in this research associated with data collection and analysis. The initial phase of this research (phase one) uses quantitative approaches only but then the subsequent phase two follows the more sophisticated method of concurrent triangulation discussed above.

3:5 Overall design of this research.

Figure 5 illustrates both the qualitative and quantitative research methods used to generate the research data discussed in this thesis. This Figure presents the methodology undertaken for a concurrent triangulation design as suggested by Teddlie and Tashkorri (2008) and illustrated in FFigure 4, demonstrating how each part of the data collection interrelate and allow greater understanding of the phenomenon (managing asthma in school) when synthesized and analysed together.

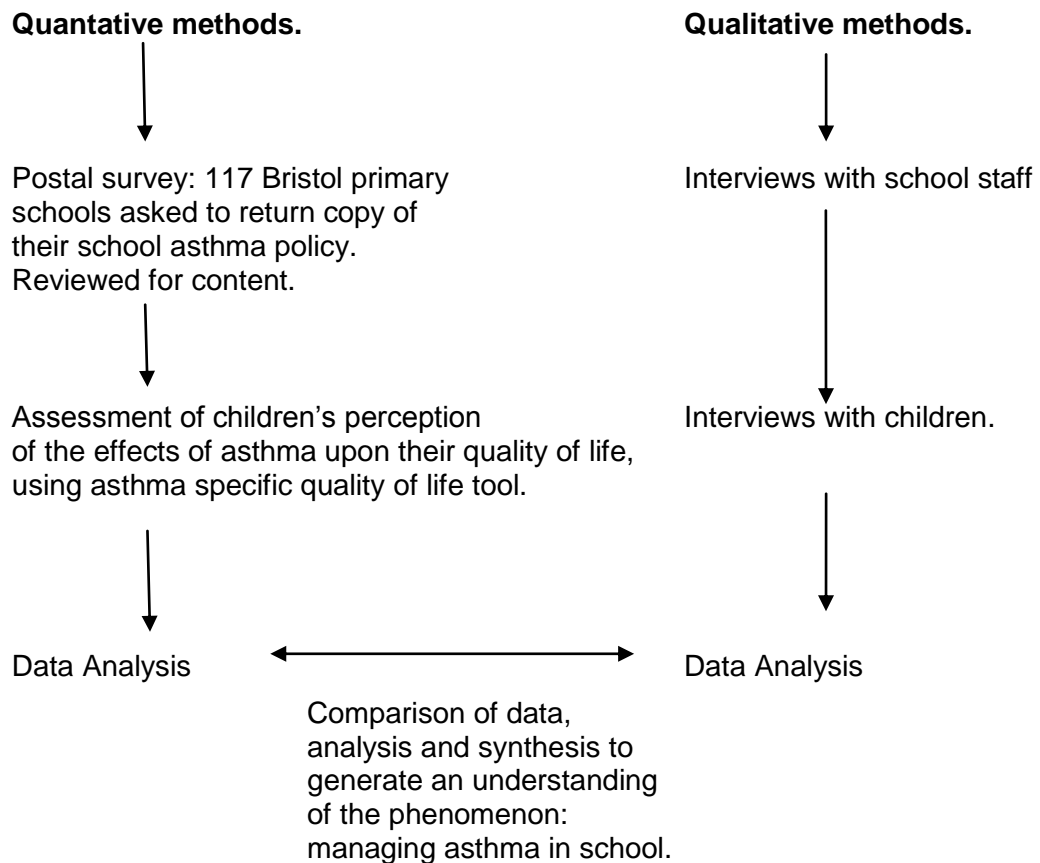


Figure 5: relationship between qualitative and quantitative methods of data collection.

The initial schema adopted for the application of faculty research ethics approval for the research data collection is outlined in Figure 6. Within it the major phases of data collection and analysis are presented.

Explanations and discussion of methodological issues are considered in section 3:6 in connection with the time frame and schema described.

Following the schema in Figure 6 the methodology chapter discusses sequentially each key stage (data collection points). This includes the justification for this method of data collection, a clearly identified research population and the associated methods of data analysis.

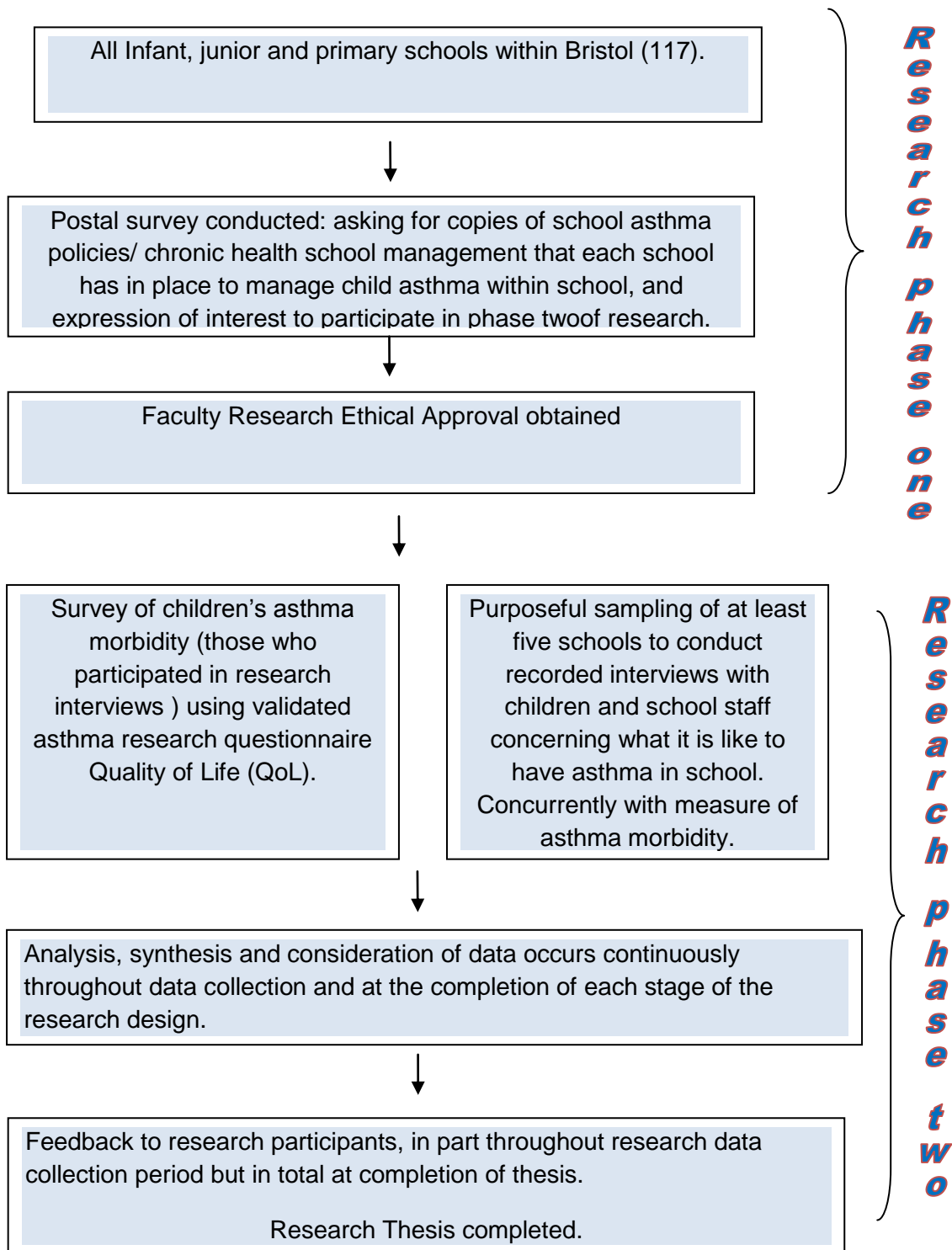


Figure 6: Schematic overview of the major steps in this research design.

Each of the 117 schools providing primary education within Bristol was asked to participate in phase one of this research (return of their school asthma policy or related document), and then 15 schools who consented to participate in phase two were selected to continue into phase two of this research.

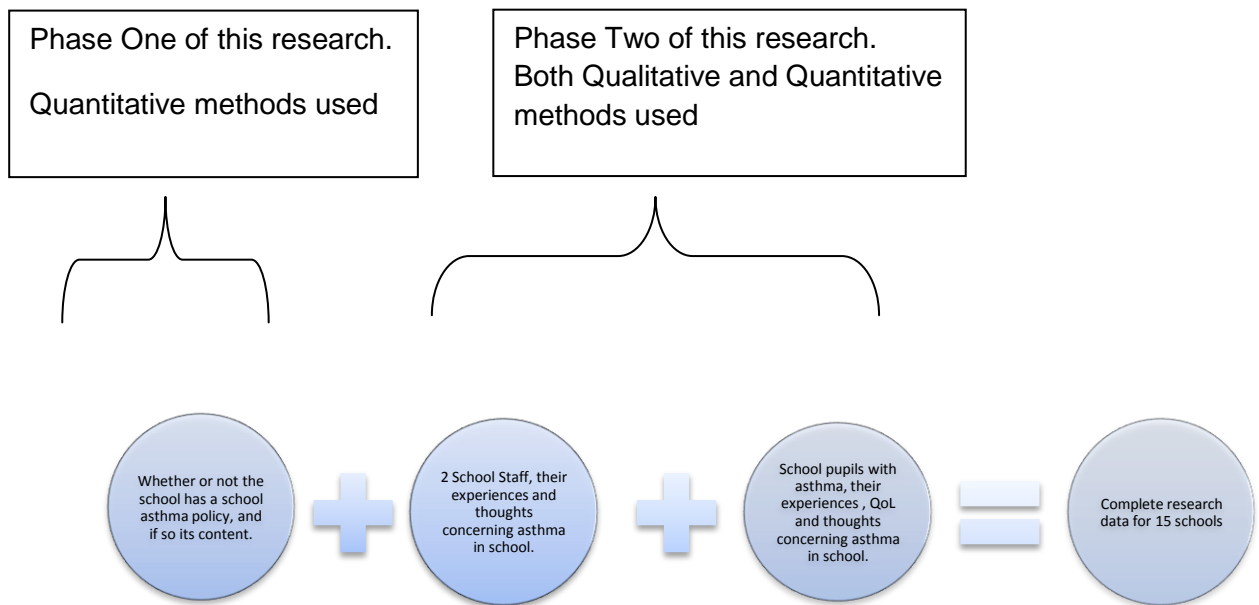


Figure 7: how research phases one and two link together.

3:6 Methods used.

3:6.1 Choice of geographical location for data collection and conducting this research within primary schools.

The area of the United Kingdom that was chosen as the location for this research is that of the city and county of Bristol. Previous thoughts had considered the geographical area of 'Avon' but, adopting a pragmatic approach, it was not possible to investigate a larger study area due to the practical issues and time constraints that one researcher experiences.

Additional reasons for locating this research within Bristol focus upon the higher than UK average prevalence of childhood asthma (Francis 2001). Figures suggest that as many as 33% of children aged 11-16 years within Bristol experience asthma or asthma related symptoms (Francis 2001, Salisbury *et al.* 2002). Within the UK the range of childhood asthma prevalence is between 29 -32% (ISAAC 1998). This evidence would suggest the possibility of a large number of potential research subjects and that perhaps the management of asthma is of interest to Bristol schools. Previous research that I have undertaken within Avon (Francis 2001, Salisbury *et al.* 2001) in the field of asthma and childhood indicated that asthma management within school and schooling is an important issue for young children and is not explored as yet and in particular within Bristol.

Sections 1:2 and 1:5 present a summary of the personal and professional reasons for locating this research within primary schools. In addition the justification for researching within primary schools results from the diversity in physical and emotional development in the ages of

children within this setting (Bee and Boyd 2005, DCSF 2007a). Children in the early years of primary schooling are nurtured and supported in their decision making, with the curriculum acknowledging that these children have only limited understanding of cause and effect resulting from their actions (Gardner 2001). However, children in the later years of primary schooling are expected to take responsibility for their actions and understanding of the events precipitating their actions and the associated consequences (Wagg and Brown 2001). Similarly this follows arguments within the BTS/SIGN 2009 (and earlier) asthma management guidelines which support children progressing through primary schooling being encouraged to take responsibility for their own asthma management. Consequently exploring asthma management within primary schools was considered to be an appropriate setting for this research since the developmental journey that children travel is of interest and relevance to the journey that children make in managing their asthma.

Liaison with Bristol City Education Department has occurred. They were fully informed of the research project and its aims. Permission was sought and given from them for the research project to take place.

3:6.2 Overarching ethical considerations.

There are a number of ethical issues inherent within this research. These include working and researching with vulnerable subjects, in particular children in an area where parents/ carers are not normally present. This will be discussed in the subsequent paragraphs in this section and in further detail in section 6:2.2. However, school staff are also potentially vulnerable in this research since they can be coerced (by others within the school) to express a view that they do not hold, or to disclose information concerning their care and management of pupils with asthma that causes them distress to recollect, or that they felt was

inadequate upon reflection. Consequently, many of the ethical considerations within this research will be addressed where they are considered relevant (this is within this methodological chapter and also within subsequent research findings and data chapters where specific issues are considered).

Of particular concern in this research is the issue of including children as key research participants and this will be addressed at this point in the methodology to acknowledge the importance of this issue. This considers and accepts that the principle of ethics (in a research context) is defined as a set of moral principles that pertain to treat participants fairly and responsibly throughout the research process (Williamson 1981). *Prima fasciae* directives inherent within all UK guidelines associated with undertaking research with children include gaining informed consent, only paying expenses to participants, limiting guarantees of confidentiality and protecting participants (Barnardo's 2002, British Psychological Society 2000, Gillick v West Norfolk and Wisbech 1985, Medical Research Council 2004, National Children's Bureau 2003, Royal College of Paediatrics and Child Health: Ethics Advisory Committee 2000, Royal College of Nursing 2004). UK based guidelines exist in relation to undertaking research with children and whilst these guidelines have commonalities they also disagree in respect to certain key issues (Twycross 2009) and it is often the individual situation that dictates the research ethical principles.

The key issues considered and acted upon when researching with children (considered vulnerable subjects) in this research context were:

- The nature of their vulnerability. Within this research it is assumed that primary school aged children cannot give full informed consent to participant as they are deemed not of an age and emotional development to understand the full consequences

of participation. Furthermore, the children with asthma in school are also a discrete group who by being involved in this research identify their illness to others who then act differently to them as a consequence of knowing that the individual has asthma. Finally the children in this research are a 'captive group', they could be made to participate because the school governing body and staff have agreed to participate in this research and thus the children themselves could feel that they have limited opportunities to decline to participate.

- Gaining informed consent;
- Gaining and maintain assent to participate;
- Allowing non –participation in research and withdrawal at any time without any prejudice or consequences to the individual;
- Maintaining confidentiality tempered with the requirement to identify and report to key people any issues arising under the auspices of the school 'child protection policies' ;
- Developing 'trust and rapport' with the children in order to explore their understanding and experiences of managing asthma in school;
- Generating a feeling of 'reciprocity' (Fingerson 2002), in essence ensuring that the children gained from the research experience. In this research this occurred by developing an atmosphere in which the children not only took something physical away from the research (their art work) but also addressed their questions or concerns at an appropriate juncture, reducing the power inequality between the researcher and the researched (Hallowell *et al.* 2005);
- Not allowing or minimising harm (both physical and emotional) that may arise as a consequence of participating within this research.

3:6.2i Ethical principles considered in relation to working with children.

Williamson (1981) defines ethics (in the context of research) as a set of moral principles pertaining to treating participants fairly and responsibly throughout the research process. Please see section 3:6.2 for an overview of the key ethical considerations in context of this research.

Research with children (defined as people younger than 18 years of age) is supported by many as important to undertake (Royal College of Paediatrics and Child Health (RCPCH) 2000), but children are seen as particularly vulnerable in this process (Medical Research Council (MRC) 2004, Twycross 2009). In part this is as a result of unequal power relationships as discussed in section 6:2.1 and children not being able to consider the consequences of their actions as regards giving informed consent to participate (Piercy and Hargate 2004, Gillick v West Norfolk and Wisbech AHA 1985). Consideration of the effects and influences of research upon both researcher and participants is much discussed in academia (Silverman 2004, Hansen 2006) and in practice (National Research Ethics Service (NRES) available online). Consequently key ethical principles should be addressed in any methodological discussion relating to research philosophies and principles inherent within the chosen research methods.

In carrying out a project, or research there is inevitably some intervention in the life of another. Consequently it is expected that both the ethics and associated consequences are considered since it is expected to have implications for how subjects and objects are valued, opportunities framed and resources allocated (NRES 2010). Schostak (2002) states that the research subject is subjected to the

gaze of the researcher, reduced to being of value as data to be drawn under the explanatory voice of the researcher's textual representations. The principles of ethics are set out in order to temper this power, and the developed protocols may help in this or they merely add more evidence and support for this unequal relationship (Schostak 2002).

Taking into account this opening a door into the life of another and portraying them for all to see will have many consequences (Williams 1981, Hanson 2006), the majority of which are unpredictable and never to be seen by either the researcher or the research subject. The 'little' portrayal contained within this thesis will be sent on a journey from reader to reader. Its power to act in the lives of the other will remain largely unknown. The intertextual plays that emerge as the messages are snatched from one set of circumstances and placed into others are beyond prediction.

Protecting the value of all the research participants, respecting and valuing their participation is thus axiomatic in all research with fellow humans. However, protecting how their stories will influence others cannot be confirmed and the best that can be offered is assurance that key principles of ethical research are demonstrated. This then allows their stories to be understood honestly against the backdrop of the research methodology. Moules (2009 page 6) states that

“undertaking research with children, young people and their families can be methodologically complex and fraught with complicated considerations”.

Considering this, research involving children should only be undertaken when relevant knowledge cannot be obtained by research involving adults (MRC 2004, RCPCH 2000). The purpose of such research should be to obtain knowledge relevant to the

health, wellbeing or healthcare needs of children (Twycross 2009, Medical Research Council (MRC) 2004, RCPCH 2000).

Informed consent should be obtained from the child, parent or guardian as appropriate, when parental consent is obtained the agreement of school aged children should also be obtained (Banardo's 2002, RCPCH 2000), with further consent or assent to participate in the research seen as an ongoing process. Banardo's (2002) state that consent to participate in the research should be actively and explicitly sought, with written and verbal information about the study available. The option to withdraw from the study at any stage should be made clear.

Three elements should be considered in respect to those giving informed consent; they must be capable of making that particular decision, must be acting voluntarily and must be provided with sufficient information to enable them to make an informed decision (DH 2001). National Research Ethics Service (NRES) (2010) state that children under the age of 16 can give their consent to take part in a research study if they satisfy the criteria of Gillick competence (see section 3:8.2): they have been counselled and do not wish to involve their parents, they have sufficient maturity to understand the nature, purpose and likely outcome of the proposed research. However, working with younger children it is unlikely that they would be deemed Gillick competent.

DH (2004) states that children, young people and their families should all be active partners in decisions about their care. In research practice many obtain the child's assent to take part in the research study, which is defined as the child's permission or affirmative agreement to participate in research (Broome and Richards 1998). Piercy and Hargate (2004) state that assent is an opportunity given to children to express their opinions and concerns

surrounding participation in research, thus providing them with a formal means to be included or excluded. Twycross (2009) states that considering ethical guidelines and the issue of assent and consent there is little difference between the two conditions. However, best practice would thus be to obtain informed consent and ensure assent was obtained and ongoing from children in the research process.

Limiting guarantees of confidentiality is addressed in several ethical guidelines Barnado's (2002) and the MRC (2004). Safeguarding children is everybody's responsibility (Twycross 2009), but possibly situations can arise in which information may be divulged that indicate the child's well being is at risk. It is this type of situation, although rarely occurring, that adds another dimension to research confidentiality since it is usual to assure research participants that their information will be kept confidential and maintain anonymity of the participant. However, working and researching with vulnerable groups dictates that attention and thought must be given to the issue of confidentiality. Barnado's (2002) state that guarantees of anonymity and confidentiality must be honoured unless there are clear and overriding reasons to do otherwise. However, the Royal College of Nursing (RCN) 2004 and RCPCH (2000) state that confidentiality should always be maintained.

This conflicting guidance from some bodies to always maintain anonymity and others that this is not always to be guaranteed when the well being of the child is at risk, presents some conflict in researching with children. It would appear a reasonable approach to explain clearly to all research participants that their information will be kept confidential apart from when the well being of the child is judged to be at risk. In this situation the researcher will act to identify this to the relevant personnel and this will be fully discussed and

explained to the child, before the research and in the information leaflet and ongoing through the research data collection (Twycross 2009).

3:6.2ii Protecting children who are research participants.

Several of the research ethics guidelines working with children (Barnardo's 2002, MRC 2004) suggest that children who take part in a research study should be protected. Recent guidance from the then DCSF (2009) (available online), demands that all those who work with children in schools, voluntary organizations and in any respect with children should have undergone a criminal records check and found to not have a record. Furthermore, researchers should be appropriately trained (MRC 2004), and be aware of their limitations, aware of local facilities that can offer children support and advice if required and upset by the research study and have a breadth of research knowledge (RCPCH 2000, MRC 2004, Twycross 2009). Adherence to these criteria is proposed to be undertaken by research ethics committees, and in health care by health care research ethics committees which monitor adherence to ethical principles laid down in the Nuremberg Code (International Military Tribunal 1948) and the Declaration of Helsinki (World Medical Association 2008). However, it is known that researchers working in other disciplines may not always need to seek ethical approval from a research ethics committee (Twycross 2009), posing the situation where the ethical behaviour and moral values associated with the research rests ultimately with the researcher.

In this research the key principles of ethics and malfeasance in respect to conducting research with children are upheld throughout the process. The children are involved in the research in as far as their pictures and discussion about their experiences and art work is relayed back to and

with the research participants (children). The children are involved in the evaluation of the research process, results and their interpretation and actively thanked for their participation demonstrating that the researcher actively incorporated as far as possible the principles of good research ethics.

These issues were considered in the construct of this research and the choice of methods used to gather the research data. They are demonstrated throughout the remaining sections of this chapter which discuss how the research methods were used and also in the relevant research findings chapters, specifically chapters four, six and seven.

It is an inherent requirement within health care based research to gain healthcare research ethics committee approval (National Research Ethics Service 2007 (NRES)). Since this research is based within an educational setting and is not involving health care professionals, children and their families in the context of health care or access to medical records it is not a requirement to obtain NRES approval. However, it is a requirement to obtain university faculty research ethical approval as part of the process for ensuring good research practice.

3:6.3 Obtaining faculty ethics approval.

Ethical approval to gather data within schools was sought and obtained in September 2008. Approval for data collection was for a duration of eight months continuing until mid April 2009. The process of completing the ethics application form ensured that issues such as data collection, storage of data, analysis and health and safety were considered carefully. Undertaken simultaneously with seeking faculty ethics approval the researcher undertook an enhanced Criminal Records Bureau check (CRB) which could be shown to all schools should they

ask for it. In 2010 all people entering schools and directly working with children are expected to have undergone a CRB check (DfE 2010); however in 2008- 2009 this was only suggested as good practice.

3:6.4 Total possible research population.

The total research population refers to the total number of individuals whom are potentially eligible to be include in the research and the population to whom the results of the research may be of direct interest. In the case of this research there are two related but distinct groups that comprise the research population. These groups are first the children with asthma and secondly the staff who work within schools who provide education and care for children with asthma in Bristol primary schools.

This can be considered in the following components;

- It is all those children with asthma aged four- eleven in full time schooling in Bristol based schools;
- It is all 117 Bristol based infant, junior and primary schools;
- It is all staff who work within the above schools providing education and care for children with asthma.

This is a large research population, which is too vast to be included totally as the whole research sample, thus the following methods have been constructed to allow selection of a sample suitable in order to answer these research questions.

3:6.5 The process of recruiting and selecting schools.

All infant, junior and primary schools were contacted within Bristol Local Education Area (LEA) and asked to participate with the project (117 schools in total). This initial contact was in writing and is referred to in the schemas named Figures 5 and 6 as the postal survey of Bristol infant, junior and primary schools, phase one of the research.

Two questions were asked, the first was to have a copy of their school asthma policy, or if they did not have a school asthma policy their chronic disease school management policy returned to me in a Stamped Addressed Envelope (SAE). The second is whether or not they had an interest in participating further with the research, this is the second stage of data collection and involves research with both school pupils and school staff.

3:6.6 Selection of schools.

In order to allow for attrition problems such as the difficulties with arranging suitable dates and time for data collection and also school staff and governing bodies withdrawing their initial consent to participate the initial number of schools selected into this stage of data collection was 15. (further information concerning total number of schools initially interested in participating can be found in Figure 9). This was undertaken using a purposeful selection process, and was designed following the selection criteria (see Figure 8) to represent as wide a range of primary schooling available in Bristol as possible. The criteria for adopting this selection process is based upon the intent to have a diverse range of schools within the research sample. This approach will provide a wide range of experiences and management practices for analysis. In order to reduce any researcher subjectivity (Denscombe

2002), the selection criteria contains a number of factors that are considered educationally (according to OFSTED 2008) important in generating the ethos of the school and management practices. Figure 8 illustrates the factors that were considered in the selection of 15 schools into phase two of the research.

These schools are considered from the pool of all the schools that had returned their replies in phase one indicating that they wished to participate in phase two of this research (from a total number of 54 schools initially interested in participating).

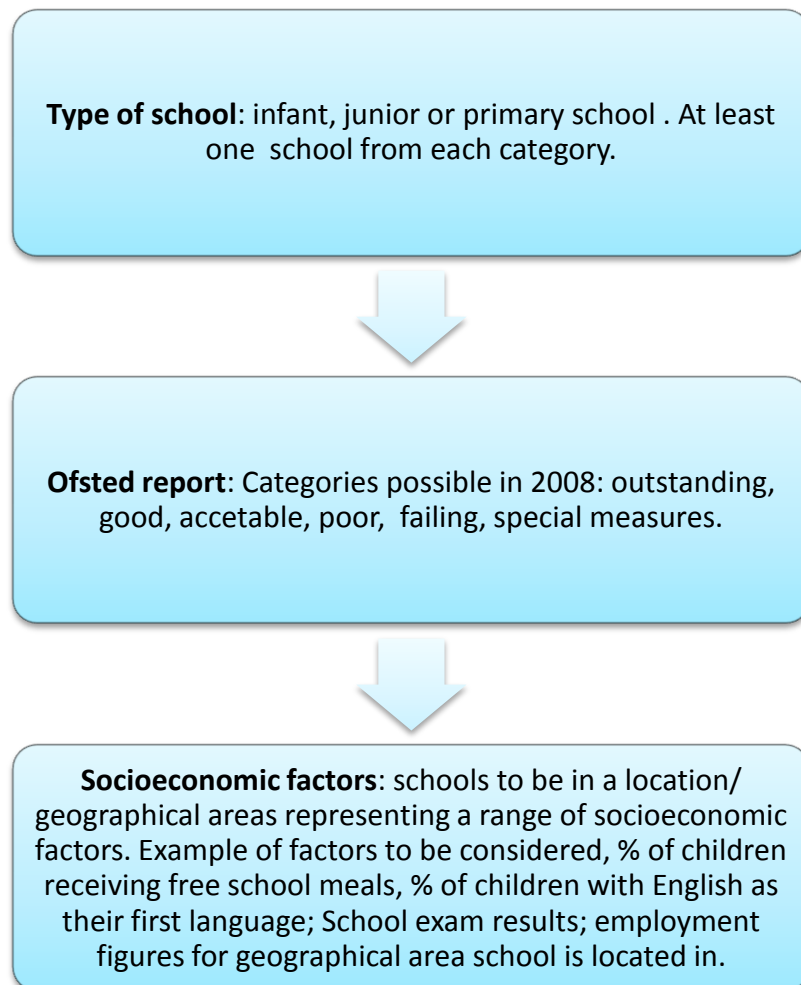


Figure 8: Key factors considered in school selection criteria.

It was not possible to have schools that represented all the selection criteria listed in Figure eight above. For example, no schools that agreed to participate in the research had received an OFSTED report indicating that they were failing or on 'special measures'. However, in qualitative research purposeful sampling is an accepted methodology (Bowling 2005). In this research context the aim is not to have research data that can be transferred/ applied to a wider population. Rather it is to obtain an understanding about the experiences of managing asthma in a wide range of primary schools within Bristol and thus this selection criteria is acceptable.

3:6.7 Gaining access to research participants.

Gaining access into schools and identifying and recruiting research participants proved to be a significant and challenging issue for the following reasons. One pertinent issue was that schools have a duty of care and obligation to protect and educate those children whom are on their school roll (DfE 2010). Thus any research or researcher who expresses an interest in working and researching within schools has to ensure that their research does not compromise the ethos of the school.

Contacting schools proved somewhat difficult, with the initial approach of writing to each school and asking if they could return a reply slip indicating if they wished to participate with the data collection producing a limited number of replies- two only. Telephone calls were made to three schools which provided information that the head teacher either had not received the letter or that they had not read it. Consequently the letter was redrafted in a style and format that it was felt would be appealing to the school staff and sent again. This second letter produced a far more favourable response, 54 replies. Possible reasons

for an increased response rate is many fold; one is the fact that a follow up letter often increases a response rate (Edwards *et al.* 2002) another is the style and content of the second letter.

Upon receiving a positive response from schools indicating that they wished to proceed further with the research and consider allowing research data to be gathered within their schools, the next step was to contact head teachers and discuss it further. The significantly large population of children with asthma and the increasing asthma associated morbidity of children (ISAAC 1998) provided a useful starting point for discussion and powerful persuaders to alerting head teachers to the issues of asthma in the school population. This combined with the school's genuine interest to promote the good health and well being of their pupils often resulted in conversations that then allowed the research data collection to unfurl in these schools.

Each school that proceeded to this stage involved the researcher telephoning the head teachers to discuss the research and often arranging a suitable time to visit the school and discuss the research in detail. Often this visit resulted in the researcher having opportunities to explore the school and to present a summary of the research including its aims and objectives to school staff and governors.

This was an important step in this research, and this had not been allowed formally time for it in the design of the research schema and key objectives. However, those schools that had an initial visit and thus established a relationship with this research were very keen to participate further. Comparing this with those schools that only participated in a telephone conversation with the researcher (and there was no identified opportunity to meet with the head teachers or other staff), often these schools were then too busy to find slots in their diaries to allow collection of research data when the winter term commenced. Similarly, liaison with staff that were not in senior positions within the

school produced limited research data from a lower participation response rate from children and or school staff, or significant delays in gaining access to the school.

The confirmed selection of schools to participate in this research is thus summarized in Figure nine. Once the schools were identified and confirmed as willing to participate in the second phase of this research the next stage was to identify the research participants, both children with asthma and school staff.

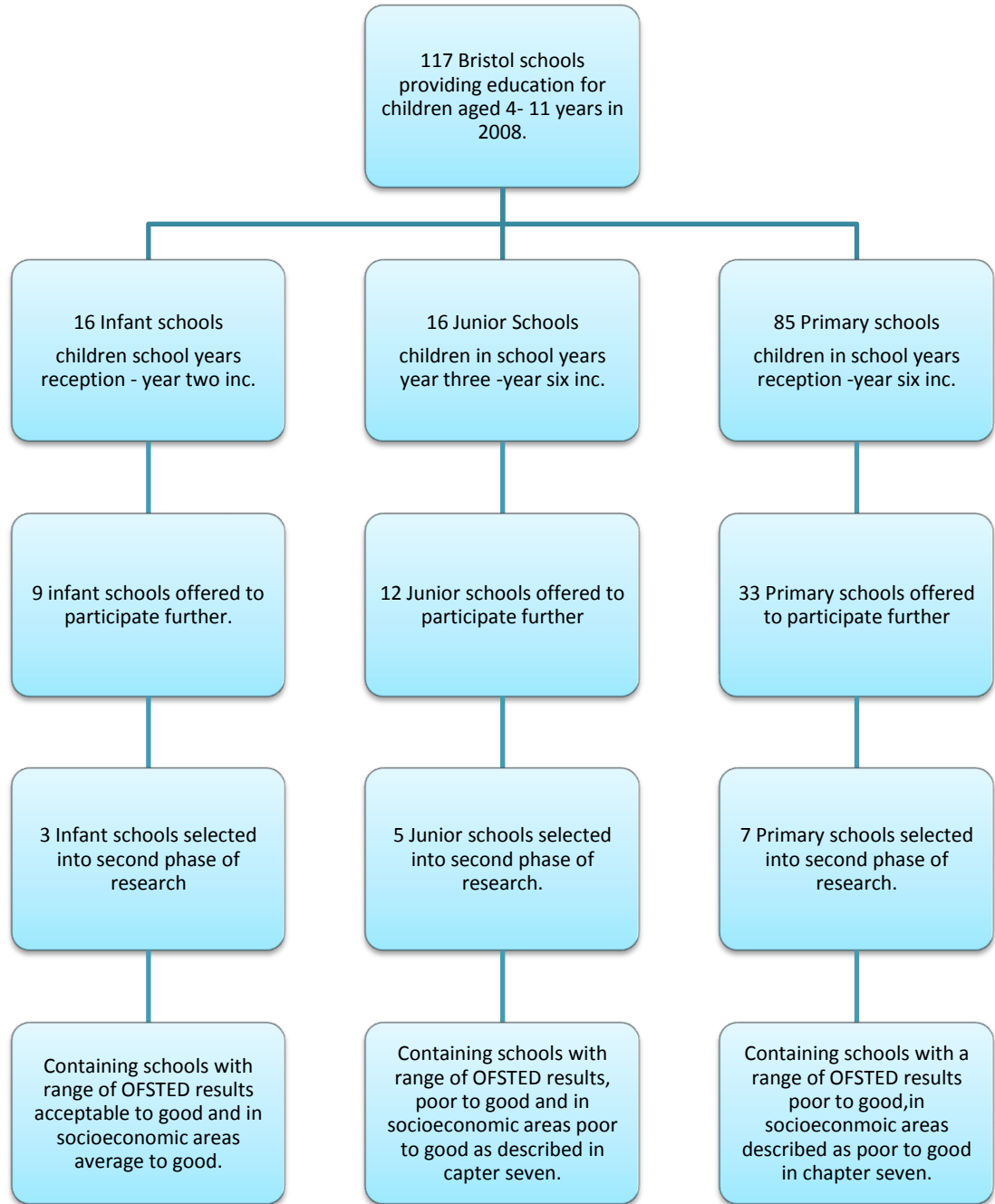


Figure 9: illustrates how 15 schools were purposefully chosen to participate in phase two of the research.

The following sections of the methodology discuss how children and school staff were selected to participate in the second phase of the research. Detailed discussion of both the selection criteria and issues

surrounding the methodology, relevant to each specific research findings chapter are presented at the commencement of each appropriate research findings chapter.

3:6.8 Outline of the selection methods applied to recruit the research participants.

Inclusion criteria for children to participate in this research was that the school was fully aware that the child had asthma; that the child and their parents/carers gave their assent and informed consent to participate in the research and that the children continued to give their assent to participate in the data collection phase of the research. Each school was asked to identify all the children that they know who have asthma. This is via the school pupil information sheet that is annually updated and returned to the school, and contains information concerning any chronic disease that the pupil may have.

It is important to acknowledge that this method of identifying children with asthma will exclude those children with asthma whom the parents/carers have not informed to the school. Other potential methods of identifying children with asthma in a school setting include correlating GP records of those children with asthma against school rolls, or asking children in school if they have asthma, or along similar lines asking children key questions that may allow identification of those children with asthma.

All these methods are associated with ethical problems which have resulted in their exclusion as a means of identifying children to include in this research data collection. For example correlating GP lists of children whom they consider to have asthma against school rolls will invariably identify some children who have asthma but where the school has not been informed. This would present the researcher with a dilemma

concerning the need to divulge this information to the school since it may influence their ability to care for a child against the decision of the parents not to inform the school.

Alternatively asking children key questions could result in the potential situation of children having asthma, or asthma symptoms but not having this diagnosis from their GP. This would result in the necessity for the researcher to inform the parents/carers of the children and possible further investigation for the children from health care professionals to ascertain if they do have asthma. Whilst this could have positive benefits for those children with undiagnosed asthma, it could involve a significant number of children who do not have asthma having investigations that are not required. Significant overall consideration was given to the method of identifying children with asthma, the chosen method as discussed above was used. This does not involve utilizing medical records or the researcher knowing information that is not available to the school personnel.

All children who have been identified as having asthma by the school in this method met the inclusion criteria. Each qualifying child was given by the school the information sheets and consent forms (see appendix iii) concerning the research and asked to return them to the school office by an agreed date.

Following this it was the initial aim that 16 children from each school who consented to participate in the research would be contacted by the researcher *via* the school and an agreed date for data collection would have been set. If the numbers of children indicating that they wish to participate was less than 16 then all those agreeing to participate would automatically be included in the research data collection. If more than 16 children agree to participate, randomly 16 children would be drawn from the total agreed population. The choice of 16 children was to allow for the formation of smaller groups of children to work with and gather

research information within. This number was in part formed from the initial exploration meetings within schools (referred to in further detail in section 3.6.7), who stated that small groups of four or six children could be accommodated in the school environment.

However, limiting inclusion into the research data collection phase two to 16 only children became problematic. In some schools 17 or 18 children with asthma agreed to participate and in these cases the head teachers felt that omitting one or two children only from this data collection phase would result in those children (however randomly selected) feeling left out and different from their peers. Consequently the research inclusion criterion for children was reviewed and all children who expressed positively their assent and parental consent to participate in this research were included in phase two of this research. This increase in pupil numbers participating in the data collection phase was made by the researcher to demonstrate participation with the school and school staff, and the ability to review the research process and selection criteria in order to encourage participation in this phase of the research. This increase in number of children participating in this research was directed back to the chair of the faculty research ethics committee for approval, which was granted.

Each school that was included in the second phase of data collection was also asked to identify school staff that would be willing to participate in interviews relating to their experiences of managing asthma in a school setting. Ideally each school would have identified two staff who would be prepared to discuss their experiences. This would be *via* self selection and the criteria would be that the school staff should have experiences of managing asthma within school. Whilst this might mean that some school staff that agreed to participate would have a particular issue they wished to air, this is not a reason to exclude them from the

research since it is likely that their views will have a significant impact upon the school.

Inclusion criteria for school staff was: any member of staff who was prepared to discuss their management and experience of asthma in a school context; ideally in each school one member of teaching staff and one member of school support staff to be interviewed. This was quite a low number but was a pragmatic attempt to reduce the impact of school staff being interviewed upon the business of the school, and to ensure that most schools would be able to provide some staff to interview. Including school support staff as discussed in detail in section 4:3.1 was considered important since increasingly schools' use support staff to help them deliver the requirements of the curriculum. This is in roles such as classroom teaching assistants and school lunch time supervision and thus school support staff have an important role to play in managing pupil interactions and decision making and overseeing pupils in the school day.

Interviews would be semi structured in nature, and would last approximately 30 -45 minutes. Interviews would be undertaken individually or together if this allowed greater facilitation with the school to gain research data.

Exclusion criteria for school staff is those who do not have experiences of asthma in school that they can discuss. It was also ensured that only one member from each family will be interviewed (in schools there can be related individuals working together) and returned consent forms that were incomplete.

Figure 10 presents a summary of how within each of the 15 schools selected to participate in phase two of this research, identification of both children and school staff to participate in phase two of this research occurred.

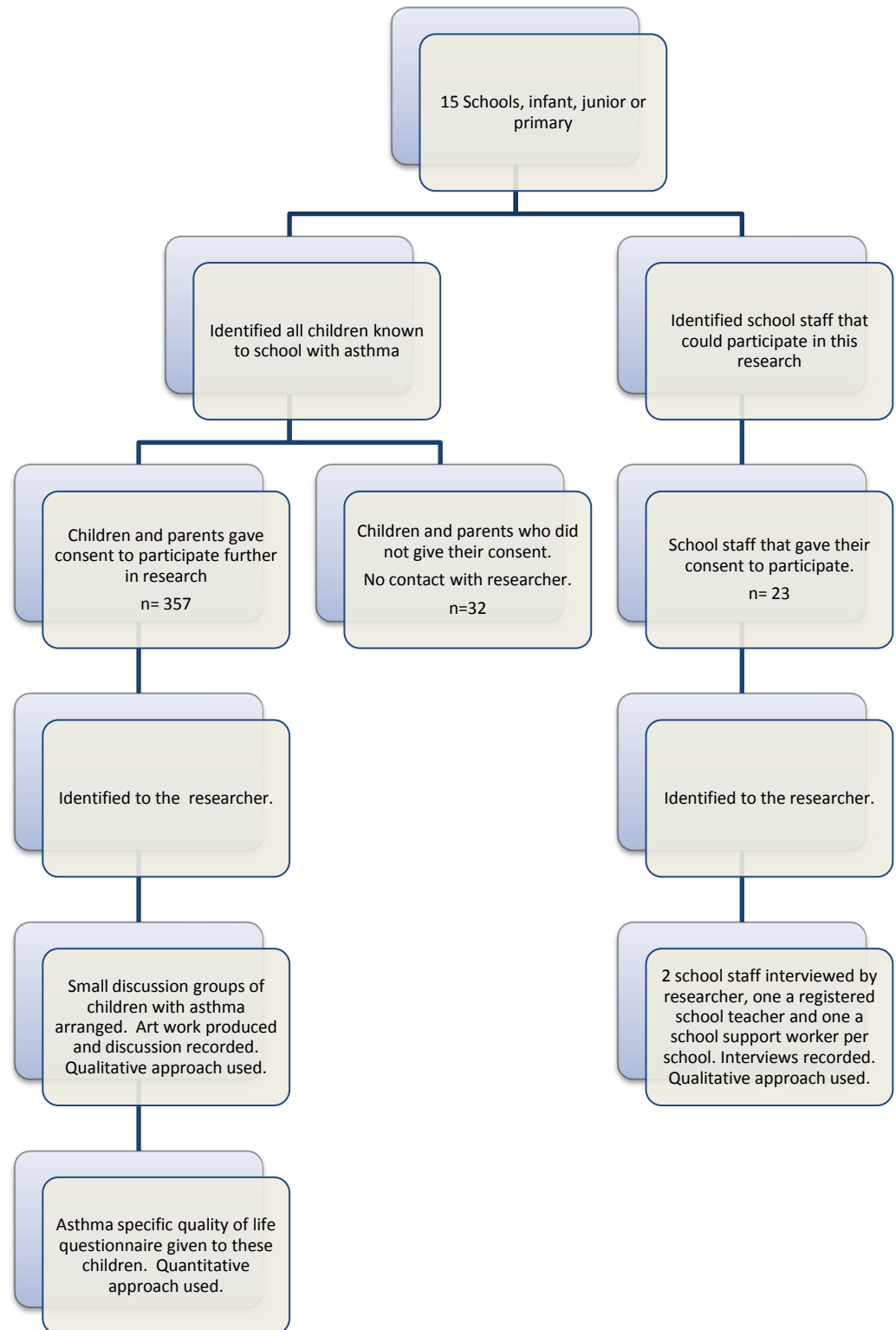


Figure 10: selection of both children and school staff into phase two of the research.

3:6.8i Amount of data considered and presented in this thesis.

In this thesis data from seven schools is considered only. Detailed reasons for this are discussed specifically at the commencement of chapters four, six and seven. This is because these are the schools for which there was all the research agreed complete data available (see Figure 7). Thus these seven schools had completed the school staff interviews, interviews with children and quality of life data was obtained.

The reasons for having missing data from eight schools that initially agreed to participate in this research, and thus excluding their inclusion in this thesis, rest within both data collection issues and withdrawal of consent to participate. The choice of health related quality of life (HRQoL) tool chosen to gather the children's perceptions of how they felt asthma was affecting their quality of life was only suitable for children aged seven and above to complete. Thus all infant schools were excluded from this part of data collection. Three junior schools did not have sufficient staff agreeing to participate in research interviews to fulfil the inclusion criteria. One primary school began the research data collection period but then became placed in 'special measures' from OFSTED, and the school and school governing body withdrew their consent to participate further in the research to concentrate upon improving their OFSTED report. Another primary school failed to provide time slots for the HRQoL data collection to occur and thus this school did not provide complete data for analysis. Figure 11 provides a summary of what data was collected from all 15 schools, indicating how many children and staff participated in the research. The eight schools that were excluded from discussion in this thesis had some sections of data collection that they failed to participate fully in, thus they are not discussed further in this work.

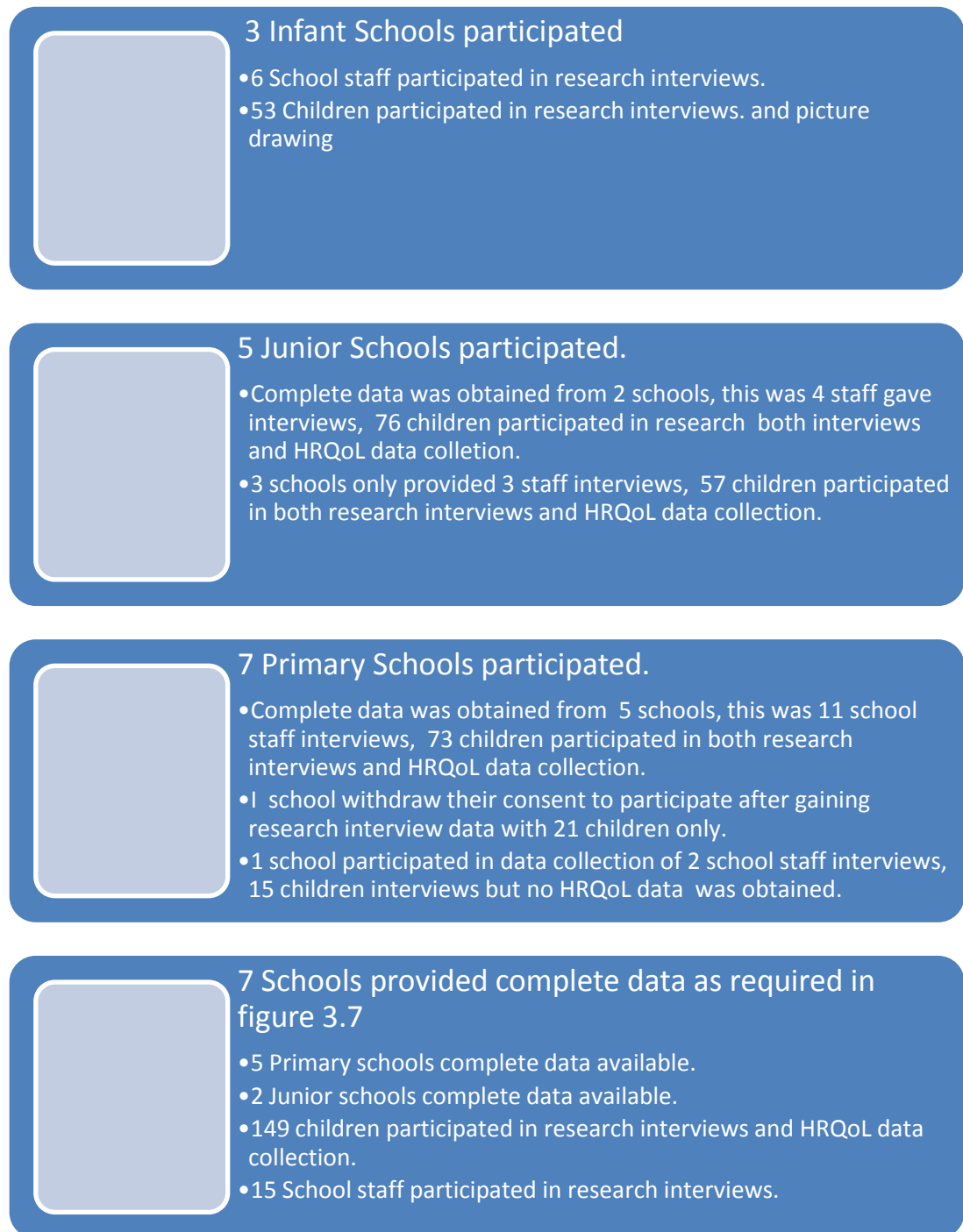


Figure 11: summarises the range of data collected from each of the 15 schools.

Data collected but not discussed in this thesis was considered against the thematic analysis arising from the seven schools included in this research, but no additional themes were apparent in the interviews not presented in this thesis. This suggests that the experiences of the seven schools presented in detail within this thesis broadly represent the situation of the eight schools not discussed further.

3:7 Consent.

Consent forms and information sheets were sent to the school named contact person for the school to give to appropriate children and they were then collected and collated back by the school. Consent is from parents/ carers for the children to participate, however there are information sheets for the children to read/ have read to them and the consent form asks if the children have been asked and given their consent that they would like to participate.

Consent forms were collected by the researcher prior to commencement of data collection. Each consent form has a unique identifier upon it which is how all information thereafter is referred to and stored either electronically or as hard copies. The original consent forms were stored in a locked filing cabinet within UWE.

Clearly expressed on the information sheets and consent forms is the right to withdraw at any time. This was reiterated at the commencement of the research data collection and the issue of ongoing consent addressed (see chapter six). Ongoing consent from the children was elicited throughout the research data collection period, this was done by verbally reminding the children about the research and asking if they still wish to participate in the research at this time. Furthermore attention was paid to verbal and non verbal body language and children disconnecting from the research data collection, which can act as

indicators that the situation, task or the environment that they were in they no longer wished to participate in further.

Schools were also given consent forms and information sheets for school staff (see appendix iv). Completed consent forms were returned to the school office and collected by the researcher alongside the children's consent forms. A suitable time and date to interview the school staff was arranged at this point.

At the commencement of the interview the school staff were once again reminded that the interview was voluntary, they could withdraw at any time and that the interview would be recorded. Attention was paid to the issue of ongoing consent, as it was with researching with children; however it was expected that the school staff would be able to articulate their desire to withdraw from the interview at any stage.

3:8 An overview of the total data collection methods.

Those children who were research participants were placed within small groups; these groups were between four and eight children. The construction of these groups was dependent upon the school and logistics associated with the school environment. Fostering a supportive environment for the children who were research participants was essential in order to maintain the prime aims of research ethics, maintaining their well being and promoting their interests (Twycross 2009). This would have a positive effect upon the facilitation of good quality data and exploration of issues that arose during the research group interviews.

During these groups the children were asked to think about their asthma and discuss times when it was difficult for them to manage in school, or

times when they found it easy to manage their asthma. Furthermore, they were asked to consider what helps them manage their asthma and what hinders them. (Please see appendix vi for an outline schema followed when gathering child related research interviews).

In these groups the children were directed to draw pictures explaining more about their asthma. They could use a wide variety of media. Whilst drawing pictures they were asked to explain their pictures and have opportunities to discuss their thoughts around asthma and how they manage it at school. The sessions were approximately 40 minutes long and were digitally recorded in their entirety. Field notes were written as soon as practically possible after the session.

The pictures were digitally photographed at school after the session by the researcher and the image kept electronically. The original pictures were then returned to the children for collection by them in school if they wished. Only the researcher was able to link the unique identifier with a particular child in a specific school.

The children only had one digitally recorded session with the researcher. Please see chapters six and seven for more detail concerning methods and methodology linking research findings with methods used to work with children.

Quality of life indices (which provided quantifiable information relating to the children's perceived asthma morbidity) was assessed in each child research participant after they had completed the research interviews. Thus each school would have all the children whom had agreed to be research participants involved in the qualitative research interviews and then these children would complete the quality of life questionnaire. Please see chapter seven for an extensive consideration of the methodological issues regarding the choice and use of asthma specific quality of life questionnaires.

Once a completed consent form was received a unique identifier (ID) was given to the staff research participant. Permission to record the interview was ensured. Transcription of the digital recording refers to the ID number only of the participant. The time of this interview was agreed by both the researcher and the research participant and occurred in school.

School staff were asked to discuss their thoughts and experiences concerning asthma management in their school. This might be a significant asthma incident that they had to manage in school, or their thoughts concerning their preparation for managing asthma in school children. This type of approach is similar to the initial interview questions used in a free narrative approach widely used in psychosocial research (Hollway and Jefferson 2000). Its strength lies in the fact that the research participant is free to talk widely about their experiences without having to directly respond to preset and predetermined questions in a structured interview. Furthermore, this research area does not have a wide literature base and it would be difficult to consider possible questions from published work in this context. (Please refer to appendix v for an outline schema followed in the research interviews with school staff).

Recorded interviews were analyzed following that of standard qualitative approaches and consideration given to content alongside field notes. Thus all recorded interviews were transcribed verbatim. Together with the field notes this allowed for exploration of situations, context and the influence of environment. Detailed discussion of methods of analysis are presented in each subsequent chapter of this thesis presenting research findings and results. The images and artwork produced by the children

were analyzed according to methods recommended by Brousinne (2008) and Harper (1998).

The content of the school asthma policies received was described, other information received at the same time pertaining to school asthma policies is also considered. Quality of life questionnaires, were analyzed as per their instructions. Their synthesis and analysis was made following this with reference to the relevant to the research situation and questions.

As discussed in the introduction to this thesis, the decision to use mixed methods has led to this thesis following a mixed methods structure. Thus the research findings chapters following this methodology address key issues relevant to method and analysis as well as presenting the research findings.

3:9 Summary of methodology chapter.

This methodology chapter has thus presented an overview of the key principles considered, the ontological approach taken and the justification for a mixed methods approach. The justification of the research methods used and the construction of the research design has been discussed. Consideration has been given towards demonstrating ethical requirements and principles of good research practice, including protecting the interests and rights of all research participants. Further detailed deliberation concerning the issues relating to the methods and associated methodology are then examined in more detail preceding each relevant research findings chapter.

This structure of the thesis has been adopted in order to help the readers understand and locate further relevant methodological and

issues of pertinence to the research findings as they are discussed in this thesis. Thus issues of mixed methods and synthesis of the research findings for example are presented in chapter eight. The following chapters now consider the research findings in their methodological context.

4: School personnel's experiences of managing pupil asthma in school.

4:1 Chapter outline.

This chapter will outline both the key issues associated with the chosen research methodology and the method used to obtain this data (interviews with school staff). Following this both the analysis and subsequent themes that were generated will be discussed. However, full recourse to both the literature review and research questions in detail will be left for the discussion concluding this thesis.

A qualitative interview based approach was taken to explore school personnel's knowledge, attitudes and understanding regarding asthma management of children with asthma in the school setting.

4:2 A discussion of key specific relevant methodological assumptions.

Ideally it should be possible to assume that both the interviewee and interviewer assumed a relationship within the interview that allowed for the maximum amount of frank and free exchange of information.

However, it must be acknowledged that this idealism may be hard to maintain in the interview and subject to a variety of situational factors outside the control of the researcher (Hollway and Jefferson 2000).

Following standard and accepted protocols related to analysis of interview data the following methodology was adopted. Iterative thematic analysis was undertaken which involved identifying themes in the interview data. Areas of interest were suggested by the research problem (what are the experiences of managing asthma in school), the research questions (what do school personnel understand about the management of asthma in school and what is their influence) and a desire to formulate an understanding of how these were linked.

This involved focussing upon the way and frequency a theme is presented and then this was linked to outside variables such as the role that the school staff member had within school, according to method cited by Ritchie and Lewis (2003) and Robson (2002).

Iterative/thematic analysis is clearly located as central to interpretive sociological tradition (Adib Hagbaghery *et al.* 2004, Brett *et al.* 2002). Adopting an approach that allows meaningful data analysis but does not prescriptively dictate the whole ontological and epistemological stance of the research process and question is crucial. In the consideration of this method of data analysis an iterative thematic analysis approach was perceived as a reasonable and credible approach to the analysis of this data in consideration of the research questions.

This approach is considered “particularly conducive to a flexible research design” (Hansen 2006 page139). Especially a research design in which patterns and themes identified in the data already collected are used to re-focus or adapt research questions and data collection tools, such as interview guides or focus group questions. Researchers conducting an iterative/thematic analysis use a variety of techniques to identify ‘interesting’ sections in the data. Coding is the best known of these techniques. Coding involves identifying sections of the data, marking them (coding) and then sorting these sections in groups of like and unlike. Precisely how researchers code their data is strongly influenced by their training and the particular type of thematic analysis they are using. One approach to utilize well known thematic analysis is a methodological approach known as grounded theory (Strauss and Corbin 1990; Glaser and Strauss 1967). This was not the overarching approach taken in the thematic analysis of this interview data, but it was used as a guide to aid in the process of data coding.

Whilst grounded theory is a method designed to allow researchers to generate or discover a theory it is not entirely dependent upon that goal. Grbich (1999) states that the most important focus is considering themes arising from the data, rather than being guided by ideas from the literature or existing theory. Pope, Ziebland and Mays (2000, page 114) state this process clearly

Initially the data are read and reread to identify and index themes and categories; these may centre on particular phrases, incidents or types of behaviour. Sometimes interesting or unfamiliar terms used by the group studied can form the basis of analytical categories.

Iterative thematic analysis has two important characteristics. The iterative aspect is associated with data immersion, and repeated exposure to the data. This often lasts a considerable period of time

(Grbich 1999), increases familiarity and expands a researcher's ability to make connections between different aspects of the data. Associated with iterative thematic analysis is a technique where researchers alter the focus of the research or the way they are conducting their fieldwork in response to the ongoing analysis of the data already collected. This highly fluid iterative phase often continues until the researcher considers they have reached a point of data saturation where no new discoveries are occurring. The second important characteristic of iterative thematic analysis is the use of coding. Highly systematic approaches such as grounded theory have clearly defined methods of coding. However, other researchers develop their own method from project to project and this is the style that was undertaken in this research.

Hansen (2003) states that coding helps a researcher to notice new things in their data by changing their relationship to the data, facilitating a process of reflection and discovery. Grbich (1999, page 234) states that the process of coding can be summarized as follows:

- Collecting data and ongoing analysis;
- Reading and reflecting on the data and developing codes;
- Refining codes through reading, reflection, comparison and sorting;
- Developing some type of classification scheme;
- Searching for examples that don't fit the scheme, critically evaluating, adjusting, altering the scheme in response to these;
- Re-examining typology in an attempt to generate propositions;
- Deciding on the key findings and writing these up.

The researcher is attempting in undertaking the tasks listed above to avoid reaffirming one's own assumptions/biases. Possible solutions to this problem can include using more than one person to analyse the data (Freeman and Sweeny 2001, Daly, McDonald and Willis 1992), or by reading widely both in the field and across the field (Coffey and Atkinson 1996). The third method is to include plenty of examples from the data which demonstrate the context of the themes that the researcher has identified (Hansen 2003).

Validity and reliability in quantitative research is achieved through the application of sampling, measurement instruments, statistical methods and then the associated statistical power of data analysis. However, qualitative research assumes that to some extent what is perceived as reality is socially constructed and that the production of research results is a constructive and interactive process involving participants and researchers (Hollway and Jefferson 2003). Mays and Pope (2000 page 51) state that from the perspective of subtle realism qualitative researchers want to design projects able to

“represent reality rather than to attain to truth” .

Similarly many researchers within qualitative arenas assume that the insights from qualitative research should reflect events and states of affairs that occur in people's lives (Hammersly 1992, Seale 1999). Denzin (1997) argues that a rigorous qualitative study will address questions: such as does the data appear to be accurately capturing the phenomena; and what approach to sampling will suit this study?

Grbich (1999) explains that researchers want their research to represent the experiences or behaviours of participants in an accurate fashion, and to document their own biases and assumptions, so that the impact of these on their interpretations can be evaluated by the reader. Lincoln and Guba (1985) outline alternative criteria for rigour in qualitative

research, these are credibility, dependability, confirmability and transferability.

Credibility is considered to correspond similarly to the notion of internal validity associated with quantitative research (Hamberg *et al.* 1994). Credibility of a study is assessed by examining the findings and interpretation; if the reader considers they represent some type of truth they are deemed credible. The dependability of a research method is related to the clarity and transparency of methods and analysis. It is expected that the research process will provide a clear account of these.

Confirmability refers to the importance of neutrality in research and establishes that the researcher has tried to avoid distorting the reality they are describing. This is often achieved by the researcher conducting a reflexive analysis, describing the analytical process and including large amounts of data in any written reports. This enables other researchers to

“judge findings and results as reasonable looking into [the] data” (Hamberg *et al.* 1994, page 179).

Finally transferability, since the results from qualitative research are rarely able to be generalised. Qualitative results are usually derived from relatively small purposeful samples and presented as interpretation and description. None the less results may be transferable. Lincoln and Guba (1985) state that if the study context, methods, sampling and results are clearly outlined, it is possible for the reader to decide if the results are relevant to other similar situations.

4:3 Method of data collection and analysis.

4:3.1 Selection of research respondents.

Primary schools that participated in this research were asked to identify school personnel that would be prepared to participate in a recorded research interview which explored issues discussed in sections 4:1- 4:2.

Each school was asked to identify a minimum of two members of staff who would be able to discuss their understanding, management and role in the care of children in school with asthma. Ideally one member of staff would be a qualified teacher and the other would have a school support staff role such as a class room assistant, or school meal assistant (SMA) to represent the views of non-qualified teaching staff in school settings. School staff would volunteer to discuss their role and understanding of asthma who met the above inclusion criteria from within each school. Interviews were to be conducted individually, to allow breadth of knowledge and individual thought to be expressed. However, in three cases due to the limits of time within school both members of school staff that agreed to participate were interviewed together in the same interview.

It was anticipated that each interview would have a duration of between thirty and forty five minutes. The interviews would be digitally recorded and then transcribed verbatim, field notes would be written and the interviewees would be given a copy of the transcribed interview.

Transcription would ensure anonymity of the interviewee, the school and

school pupils. Full informed consent from all research interviewees was obtained (see appendix iv for consent and information forms).

An outline protocol for the interview with school staff is included in appendix v. The research interview protocol was adapted as the research data was gathered, which involved in initial interviews having an interview protocol and key questions to be asked during the interview. This became far more fluid in context with increasing confidence of the researcher and understanding of the environment; ensuring that the key questions were asked but often these were covered just by listening to the interviewee discussing their thoughts, emotions and examples related to asthma management in the school setting. Similarly, the majority of the interviews were conducted individually, but in the case of three schools their school staff personnel interviews were conducted in pairs in order to gain data. Since time constraints within school meant that unless this was undertaken only one research participant would have been interviewed and not two. This heuristic approach to utilizing interview and slight method changes within the interviews in terms of gathering data individually and in pairs is allowable in this paradigm, especially utilizing pragmatism as the ontological principle.

Field notes were written up as soon as possible after each interview. Reflexive critical review after each interview was written, acknowledging the role of the researcher in the interview and the process of data collection that was influenced by both the interviewee and researcher. Certainly the researcher became 'better' at conducting research interviews with time, if better is measured purely by not speaking for too long and allowing the research respondent time to consider their answer and explore it further. However, at times the research respondent asked direct questions of the researcher concerning how medication worked for example, or where could they find further information and these

questions were answered either at the time or at the end of the interview. Certainly this type of situation demonstrated that the researcher was perceived as 'knowing more' concerning asthma than the research respondents and thus 'fair game' to help the research respondents improve their knowledge. It must be acknowledged that this was more true of some interviews than others and this is expressly commented upon in some of the themes presented below.

4:3.2 Description of respondent characteristics.

In total 15 school staff were interviewed, three interviews were with two members of staff concurrently and nine were with staff individually. In total seven qualified teaching staff were interviewed, two were either a headteacher or deputy headteacher, and all seven teachers ranged in experience from teaching for three years to teaching for thirty years. Eight school support staff were also interviewed, this included three first aiders, three school meal assistants (SMA), two class room assistants who had some NVQ qualifications, the range of time in employment within the school settings ranged from 18 months to 23 years. The participants in all represented a total of seven primary schools within the city of Bristol.

This purposive sampling of school staff was chosen to ensure that all research respondents were able to discuss their role of asthma management in the school setting, that they did in fact have something to say and that they were able to discuss this during the interview. Also the decision to interview both support staff and qualified teachers from the same school was consciously made to represent the variety of staff that provide supervision and care for children during the school day.

4:3.3 Method of data analysis used in this stage of the research.

Thematic coding followed a similar process to that listed in section 4:2, resulting in the generation of themes and sub themes from the data. The researcher adopted two of these approaches to help with ensuring that the data coding was undertaken to minimize personal bias, and maximise credibility, transferability and dependability of the data. These approaches were to read widely around and across the field and also to ensure that in the writing up of the thematic analysis many examples from the data were included. Examples of interviews and initial coding was shown to research supervisors to ensure that the process of collecting and conducting interviews was appropriate and gain initial feedback concerning early thoughts surrounding data. However, the process of immersion and reflection that followed later after gathering all the research data allowed far greater analysis and understanding of the data set, than in the early stages.

The following section now discusses and presents the key themes from the transcribed data.

4:4 Emergent themes from the research data.

Consideration of each interview following its transcription and correlation with field notes and reflective notes from the researcher revealed recurrent themes and also interviewee specific issues/ content. Exploration of the recurrent themes will be discussed first and illustrated where appropriate with specific quotes and also located within relevant

and appropriate research literature as required. Figure 12 provides an illustration of the main themes emergent from this data.

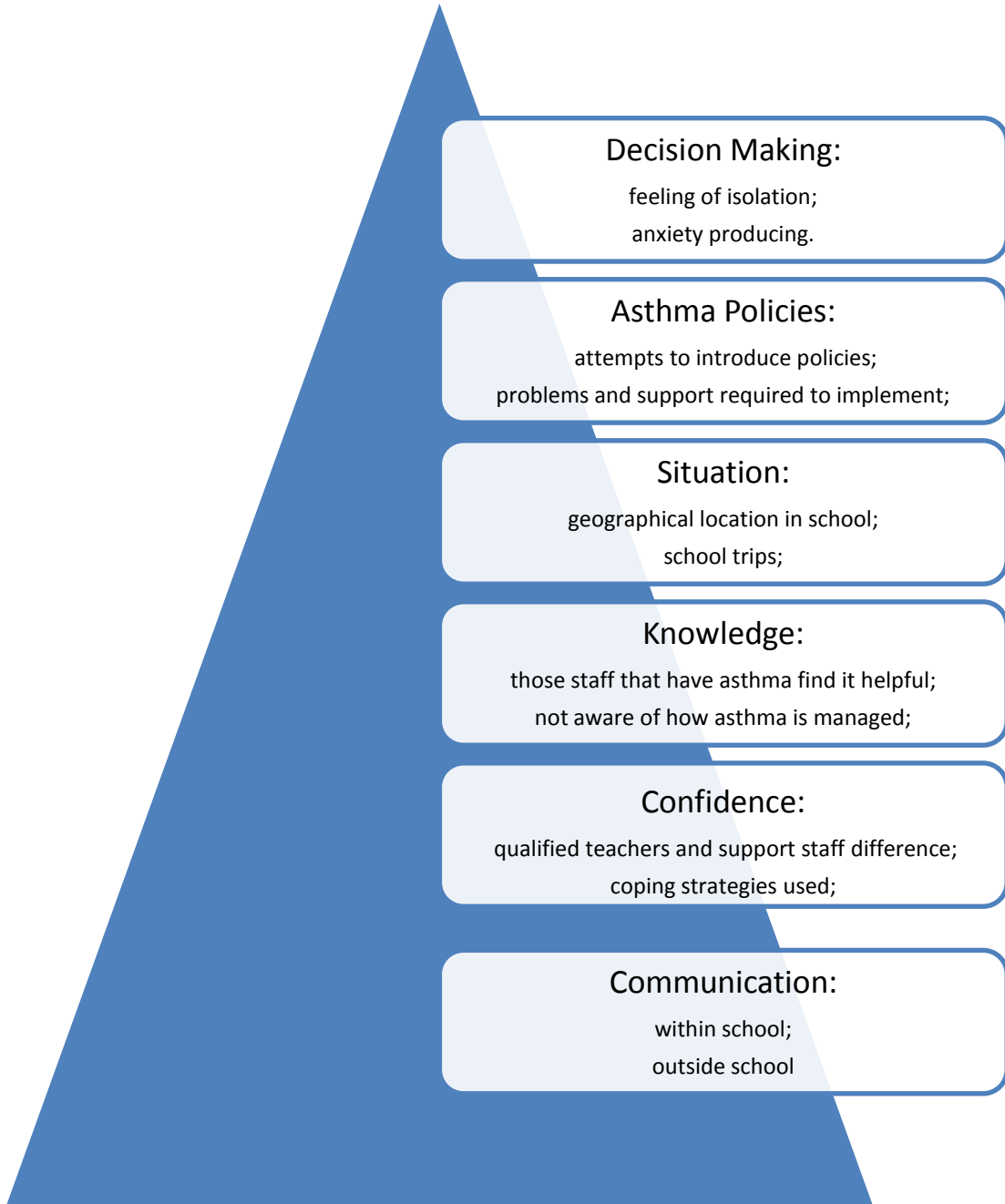


Figure 12: The six main themes emergent from this research data.

These themes are discussed fluidly below and presented for consideration, with relevant extracts from interviews included.

4:5 Discussion and consideration of the thematic content from these research interviews.

4:5.1 Communication.

Throughout all the interviews, regardless of the roles and job description that the interviewee had within the school, communication was the most frequently recurrent theme. It appeared that communication or rather problems' relating to communication was a major issue that the school personnel felt hampered their ability to provide good asthma care.

These communication issues can be subdivided further and located as communication problems within the school environment and staff, and communication between the school staff and parents/ carers and children. Consideration will be given first to communication within the school environment.

School personnel cited the following: many stated that there was no communication regarding the management of asthma in school; that they did not know if their school had a policy or protocol that they should follow and they do not know whom to contact within school should they require help managing a child's asthma. This lack of clear communication regarding policy generates high anxiety amongst the staff. It appears that each member of staff stated what they would do as an individual and thus there was no clear consistent approach apparent within each school. (This inconsistency is commented upon by the

children with asthma, see chapter six). Anxiety regarding the managing of asthma by school personnel will be discussed later in this chapter.

One participant states

18S⁵:“ and one of the things that surprised me was the fact that there was no kind of asthma policy. There wasn’t really, there was kind of procedures in place; some teachers keep asthma inhalers in cupboards; some stuff has names on; some teachers know who is asthmatic; some teachers don’t know who’s asthmatic.”

Another says regarding asthma policies and whom to contact

6S:“I’m not sure if we’ve got one, I’d not know where to find it if we’ve got one, but we do know what to do.”

The absence of a clear policy or protocol regarding the management of asthma or uncertainty as to whether or not the school had one caused much discussion from school personnel. Essentially no clear communication concerning how asthma could and should be managed in the school setting caused interviewees some discomfort when asked to reflect critically upon how they would manage asthma. This was closely followed then by generating concern within the school staff research participants, reflecting upon their own actions that this was not how asthma should be managed. For example the interviewee who stated that “but we do know what to do”, later in the interview then continued to discuss where children’s inhalers were kept in school which she didn’t know for certain, and, concern regarding whether or not ‘ventolin’ was too strong for children to have and should be limited access only.

A head teacher in one school, when considering directly the issue of whether or not the school should have an asthma policy reflected that:

⁵18 S: denotes participant direct quote from transcript of interview, S is used generically to indicate one of the 15 staff participants, 18S is thus the research participant’s unique identifier.

1S: “..I think...it’s always useful to have a policy....Yeah if you’ve got a policy its easy to hang things on, and then nobody misunderstands, you know things.”

It would appear that having a school asthma policy with clear directed communication regarding issues such as whom to inform, where inhalers were kept and who should have them and how to manage asthma was perceived to be essential for school personnel. Their comments suggested that this would help reduce their anxiety regarding how to manage children with asthma in a school setting, and generate accurate and appropriate intervention to help children manage their asthma in school.

What was considered appropriate intervention and how to help children manage their asthma in school caused significant communication issues for school personnel. It appeared that it was easier for school staff to discuss managing asthma when not upon school premises. Qualified teachers discussed school trips clearly and frequently in which they had clear guidelines from the Local Education Authority (LEA) to help in the management of children with asthma. It seemed that the use of this framework in which children, parents and school staff had both clear responsibilities and actions defined helped contain anxiety relating to school staff’s management of asthma.

17S: “We had a little girl last year that did have asthma quite bad..... I took her out on a school trip this year and I think she had an attack brought on by stress ‘cos we were going to secondary school and then part way through the trip she sort of just went into like a panic mode, which turned into an asthma attack.

CF⁶ Okay, how did you deal with that?

17S:I just sat her down made sure she had her puffer and just talked to her and tried to calm her down, get her a drink and after a little while she was okay.”

⁶ CF: indicates researcher’s question/comment/ interjection in interview.

Similarly school support staff such as first aiders and school meal assistants (SMA) reflected critically upon how they managed children with asthma in settings other than school, for example as a cub scout leader. They stated that for them in this context (outside school) and in a different role (e.g.cub scout leader) clear policy and guidelines helped provide rationale and aid in decision making when a child requires help to manage their asthma. Quite often in the absence of a school specific policy their experience of managing asthma in this outside school role 'spilled over' into their school based job and helped them manage children's asthma in school.

2S: "I had one 'cub'where he'd been given breathing exercises and actually when he had an asthma attack he didn't panic.....and I know, the tendency is its quite distressing for other people to see an asthma attack in full flow, if you're aware of what's going on and so, then you've got all the people saying, well just breath, breath freely you know. And actually that's not really what asthmatic's want to hear they just want to be put in a comfortable position and they can just, you know, kind of manage it themselves."

6S: "When I do my Sunday school, I have to do training and the Church has a good guide saying what to do when children have an asthma attack. I use my training that I had to get from Church and follow the guide then, it is much easier and I try and remember what the Church has when I'am in school."

This 'added value' regarding asthma knowledge that school support staff who have outside experience with managing asthma brought to their school based job appeared to be of great significance to other school personnel, since often it is these people who have acquired 'extra' knowledge who are asked to help when children become poorly even though the school should have identified first aiders with specific asthma training.

1S: "I, know that xxx has first aider knowledge from the Guides, so I send my children to her when they get bad since I know she can handle it, You see zzz (school first aider) isn't very good with asthma."

Communication between school staff appeared *ad hoc*, and if appropriate personnel exist within the school environment who knew

about asthma and how it should be managed this was not clearly identified to all school staff. For example it would appear reasonable that those staff who are designated as first aiders should be called upon to help with the management of children who need to utilize their asthma inhalers. However, in this research some first aiders acknowledged that they did not know what to do to help children with their asthma.

3S: “because I’d been here for so long when I first came I was just told to you know give them two puffs and they would get on with it.....and that is usually what happens.”

States one school first aider, who later in the interview discussed why she would not be the best person to call if a child was having an asthma attack, but was the one that children were asked to see by the qualified teachers.

Summarizing this issue regarding communication within school and school based staff it would appear that there was no consistent advice and policy that school personnel were aware of, except when taking children off school premises. The absence of clear policy generated individual practices and personal understanding concerning the management of asthma. Even those staff who were designated school first aiders are uncertain of their practice and responsibilities, often then relying upon their exposure in the management of childhood asthma in other roles and responsibilities outside the school setting in order to help provide asthma care for pupils in school. It would appear that clear effective communication was wanted by school personnel, from head teachers to school meal support staff the importance of clear school specific asthma policy was accepted. This would help allay the anxiety that individuals expressed when considering how they managed children’s asthma.

4.5.2 Confidence.

The effects of anxiety upon performance and the decision as to whether or not to intercede and ask for help was expressed frequently in these research interviews. A wide range of opinions were expressed from school personnel not wanting to ask for advice from others either within school or outside agencies. Another felt that because the accountability rests with them as the school first aider, regardless of the support that they might not get from the school personnel, (to be discussed later) states.....

2S:“I think again that’s probably something to do with the fact that the vast majority of people don’t realise that asthmatic people die.”

This first aider had knowledge regarding the management and consequences of an asthma attack acquired from training to be a cub scout leader which he brought to his first aider role in school. Asking for the help of the emergency services is completely reasonable and would not for him be a decision that he found difficult to make.

2S:“I think with children I would not hesitate if they were having difficulty in breathing. I wouldn’t hesitate to phone straight away.”

This first aider was unusual in this research since he stated explicitly the potential consequences of a severe asthma attack, and that he wouldn’t delay in asking for help from emergency services should it be required. This confidence in his practice he stated he gained from being a cub scout leader, not from first aid training in his school role. The notion of confidence in your own practice is a recurrent theme in this research data and it appeared to influence communication issues with all school staff regarding the management of asthma.

Those staff that felt some confidence in their knowledge and understanding regarding asthma communicated more freely about their management of childhood asthma. However, the majority stated that they did not know enough about asthma and would like to know more in order to be sure that their practice and communication is appropriate. Feeling confident is something that all school staff would like to have, and to gain this confidence they asked for clear communication, asthma policy and identified people to ask for assistance in the management of children's asthma.

Communication between school environment and parents/carers and children with asthma followed a similar pattern. It was a frequently occurring issue within all the school staff interviews. There was concern from school staff that they did not know reliably which children had asthma, what medication they were required to take and when the child might not be so well with their asthma during the school year.

2S: "I mean we don't have any what I consider to be major asthmatic children as such who have, you know issues just walking around..."

CF: do the parents tell you if they're worried about their child?

2S: Not really no..... erm well the first I knew was the fact that he kept taking it and I was like... and he said...oh... I was feeling a bit chesty at the moment.... what they're not good at is you know, and the parents as well and that's aits a communication thing within this school environment...a little bit of animosity from parents to the school, its a them and us situation"

There was a concern expressed by many school personnel that they did not know whom has asthma and what medication if any they were taking, or if they was a change in the child's asthma status.

9S: "Cos, that 's the other issue, they tend to sit there and the child stops using them [inhalers] and but they're still sat there, you know and they never.....so and then its well: do they have asthma now, or is it controlled, you know?"

CF: yes, is it, has there been a change in their child's asthma that you no longer know anything about?

9S: I'd say that doesn't happen at all. In fact the only time that would probably happen is, if as the beginning of a new year, which is this year if they send the forms home again and say does your child have asthma?"

This barrier between school personnel and parent/ carers also caused a problem when considering how, when or if to notify parents that a child has had to use their medication during the school day. One first aider in school felt that it was his responsibility to ensure that any noted exceptional use of inhalers by children should be reported to the parents, and in the absence of a rigorous protocol he did it as below in an informal manner:

2S: "Well he used his [inhaler] four times the other day. That's four times that I saw, so I'm assuming that regardless of Mr. S---, you know, he would have probably used that a couple of times but I didn't see. So I felt that four times was quite excessive, so I just mentioned to Mum, he's been using his inhaler quite a bit today."

This communication between this member of staff and parents/carers of children with asthma in his school was achieved at personal cost. In discussing how he had managed to communicate with parents/ carers he stated

2S: "Certainly in this school it's been a battle, in other places I've not come across that before and it's quite interesting.but I've not come across that before and it's quite interesting.but you can't dice with First Aid as far as I'm concerned, or those type of issues. You're either doing it right or you're doing it wrong."

Other staff from other schools when directly asked this question reported varying answers that they may tell parents/ carers, or that the practicalities of this was too much to undertake and no they did not tell parents/ carers if children had used their inhalers in school. This lack of

consistency and variation within schools relaying information back to parents and carers influences the relationship between school staff and parents.

Quotes from several school staff illustrate this below:

12S: “I don’t know when to tell people and when not, and I then wait and see if I get asked that’s the best I can do.”

14S: “...so I don’t worry any more ‘cos it like, like it can make you bad and then you feel poorly so I never do it I figure like it’s up to them [children] to tell them if they need to.”

17S: “ sometimes I might, but I don’t tell the class teacher so I don’t tell the parents...why should I?”

This is commented upon by many staff in these interviews who noted that without effective communication between parents/ carers and school staff, the management of asthma was difficult and often rested upon their own knowledge base of both the child and the disease.

One school however, appeared to have an inclusive attitude towards managing children’s asthma in school and easy access for children to their medication. This school, although it did not have an extensive asthma policy (see chapter five) did not appear to have staff experiencing quite the same ‘them and us’ communication problems between parents and school staff. A qualified teacher reported that meeting and discussing with parents is

10S: “we’re quite informal on meeting out on the playground beginning at start of days and parents feel quite comfortable just popping a note in or phoning up.”

However, in the same interview this teacher reports that one parent wanted to be telephoned every time his child took their inhaler during school. This became problematic within the school since no staff member felt that it was their responsibility to do this, and resulted in the parent rescinding their request to be telephoned every time, down to

only being informed if the child used their inhaler twice during the school day.

One deputy head stated that in response to the question would school teachers know when to ask for further help and take action/ responsibility for children becoming quite unwell that poor communication leads to complacency.

11S: “because people are.....asthma is more common although diabetes is obviously on the rise and more children have asthma..... but maybe there is complacency around the whole asthma thing. Oh I’ve got asthma, sometimes it comes with a pump [inhaler], sometimes they don’t , sometimes they don’t bring....and even parental attitudes towards asthma I think at times it doesn’t give you a full picture...”

Another respondent from a different school stated

6S: “And what usually happens when a child is prescribed medication the a parent comes in and they fill out a form with me and the form says the drug name, plus how often.....a lot of them just say as and when required....but that isn’t sufficient that’s no good.”

Consistency around communication, openness and honesty are expected in order to ensure that the interests and well being of children are protected. With distress upon both sides of the relationship this can lead to a delay in critical information and alterations in children’s health status being informed to the school. This can lead to the school not acting promptly when a child’s health was deteriorating due to not being aware of the significance. Quite clearly this was not a situation that either side would wish to generate but seemed to exist widely in this research with these primary schools. All the personnel who gave interviews in this stage of the research alluded to communication problems between school and parents/ carers and children.

One head teacher comments

1S: “one of the children you actually had today it only came to light on a trip that he had asthma and that in itself then caused slight issues because he suddenly had a pump [inhaler] falling out and nobody knew and it all, you know, those things you sort of need to know about.”

It would appear that school staff were operating in an environment which had difficulties in communication between parents and school personnel. This is then echoed and perhaps in part explains the following theme that occurred throughout the school staff interviews. All school staff expressed their view that children did not always need their inhalers when the children asked for them, and that in fact children were not always honest when they said that they needed their inhalers. This is best expressed as distrust and disbelief of what children say regarding their asthma and need for medication.

One qualified teacher actually stated this in connection with allowing children access to their inhalers:

9S: “It’s a lack of em.....essential, I don’t know, its a lack of trust I suppose.....because they think em, the child will misuse it or let other children misuse it, or some other child take it, or em.....and it’s.....the chance of it happening here or anywhere probably, is extremely remote, extremely remote.”

Others suggested that they take time to assess whether or not the request or symptoms are genuine.

6S:“....but you can see if its genuine. I think most of the time you can tell.”

13S:“I would imagine, they sometimes think they need their inhaler, like you saw.....C----- this morning, and i’d probably take them out of the classroom and say look how do you feel are you sure you need your inhaler?”

These comments occurred throughout many interviews, with the suggestion that children are not to be believed in their request to have access and use their inhaler, or that their asthma was bothersome at

that time and they require further intervention. This appears incongruous with the aims of asthma management in school aged children (BTS/SIGN 2009) that children should have readily available access to their medication in order to take control and manage their own asthma. Furthermore, there is evidence widely available that indicates that children under the age of five are able to accurately interpret their level of symptoms regarding asthma and whether or not they need reliever medication (Yoos *et al.* 2003).

This issue of distrust manifested itself in association with the ethos of the school environment in which school personnel managed children's asthma. The lack of clear communication and policy regarding asthma management within school and limited liaison with parents/carers and children directly influenced how school personnel manage children's asthma. Many school staff reported that they felt the decisions they made regarding how to manage a child's asthma would not be actively supported by their colleagues.

This can be illustrated by reference to the differing opinions regarding how to manage a child who required their inhaler when in class expressed by two differing qualified staff in the same interview. One reported that when a child states that they need to use their inhaler they ask the child to leave and walk to the office to get their inhaler, the other staff member in the same school reported that they would ask another child to get the inhaler on the behalf of the child with asthma. Furthermore, they also stated that in their classrooms some teachers allowed children to have their inhalers with them and some do not. This was illustrated throughout the interview in which two school staff members participated simultaneously in the interview but gave different answers to key questions which later they discussed without surprise at their variation in answers.

15S: "I think maybe for severe cases it maybe should be in the classroom, maybe by the teachers desk. You know out of the way."

14S: "You'd send a child maybe to go and get them [inhalers from school office], that's what I would do I think."

Distrusting children when they state that they needed their inhaler may explain why school personnel did not allow children access to their medication in the school environment. For all but one school, children's asthma medication was removed from the children's immediate environment and kept in a safe place, often this was the school office, but not always so.

Asking school personnel where children's asthma medication was kept generated a number of answers within even the same school. Some said that inhalers were in the school office, some were in the first aid room, some were with the teachers and in only one school did the children have their own inhalers in their drawer within their classroom.

There was a slight difference in the school that allowed children access to their inhalers. The staff in this school although they expressed concern that their knowledge and decision making may not be adequate, the ethos of the school as stated by a qualified teacher was:

12S: "You know, we have always maintained, you know we try, you know we are promoting an ethos of respect whether that's respecting your belief, whether it's respecting your cultural background whether its respecting your right to disagree with us, you know and that's what we're trying to encourage all of children to do. In all areas".

Managing chronic disease within the school environment required united and consistent approach from all staff whom are supporting each other (French and Carroll 1997). Without consistent support from colleagues anxiety that staff feel as referred to above becomes problematic especially in a society which is becoming more litigious and policy driven. One teacher reflected upon her previous statements concerning

how she managed a child who became unwell with asthma in her class and her decisions at that time.

13S: “But I think we’re under different strictures at school because we have these things and I wouldn’t necessarily feel because of how the world is, if we gave something to another child.....”

4:5.3 Knowledge.

School personnel felt that they did not have enough knowledge concerning how to manage asthma, and perhaps this explains why they felt anxious and not supported by colleagues when considering their asthma management. School personnel reported that they had had varying information and education regarding asthma management. This was apparent throughout all the interviews in which school personnel described medication, but didn’t know the name, or incorrectly named medication or cited how they would manage an asthma attack (incorrectly against BTS/SIGN 2009 guidelines). However, in order to manage an asthma attack it is important to recognise that a child is having one.

15S: “If I know that the child suffers with asthma, but probably I wouldn’t pick that up if somebody just started to have an attack or something.....”

14S: I mean if a child is making a wheezing sound then you would know.....because that’s what I used to do so things like that you would probably recognise wouldn’t you?

15S: Oh yes, I think I would probably, probably.....perhapssay well that’s asthma.....”

14S: I’d like to think that I recognise something was wrong.”

Those staff that were also designated first aiders had had more training and education regarding asthma in school, felt more confident recognizing signs of an asthma attack. The amount of education they had received was extremely variable and ranged from an hour in a half day programme to a few minutes discussing principles of asthma

management. Often asthma knowledge was obtained as discussed previously from other sources outside school and the LEA. One qualified teacher stated regarding training and knowledge concerning asthma

13S:“We’ve had a couple of, you know the half ‘in service’ days for medical conditions, so its been quite general. So in terms of asthma just a very minor little bit about trying to calm the child and trying to calm the child and trying to talk them through so the breathing comes and then if it’s not getting much better, try the paper bag, just to try the inhaling and the exhaling and just calm it down ...”

This extract illustrates some of the common statements made by school personnel. They discussed calming a child down, and then refer to using paper bags as a treatment (which is incorrect for the management of asthma, but correct if it is hyperventilation that the child is suffering from).

Other staff discussed more generally their knowledge regarding medication and what inhalers are called, referring to them by colour and ‘pump’s. Two school meal assistants who acted as first aiders during school lunch time discussed what they know about asthma, and suggested that because one has asthma herself she knew what to do better than the other. This type of observation and comment occurred several times in the interviews, those staff that themselves have asthma, or have close family members with asthma felt more confident in telling children to be calm.

8S:“I just let them sit down, wherever they like and tell them to breath ‘cos that what I do and I know it helps... it helps me lots”

School staff who also have asthma were more confident in discussing the use of medication, using words such as reliever medication or the blue inhaler helps. However, they still claimed that they had limited knowledge concerning the management of asthma and would like to

know more. Regardless of how they manage their own asthma, these school staff did not know how asthma may be best managed in the school. None knew or advised children to take their inhalers pre undertaking an activity that the children knew would exacerbate their asthma. Furthermore, none felt that children should have their inhalers with them in case they become unwell, in contrast to other staff who did not have asthma but some whom did consider that children should have their inhalers with them. Those staff with asthma, at times in the interviews became focused upon children growing out of it, that asthma would not be bothersome for them all the time. This was incongruous for one staff member with asthma in her interview revealed that when she was herself at school one of her friends that she was walking home with died from an asthma attack:

7S: “we were late coming out of school, you see one day and we had to run for the bus... we all saw it at the bottom of the road so we ran for it.....M--- couldn’t run she shouted out it was her asthma and to go on, so we did we left her there gasping. And later you see we found out from her mother that her attack had been so bad she died.. we were only 14 and we left her there..... I didn’t even know that asthma was that bad.... [long pause]

Strange I haven’t thought about that for years until now... you don’t you know. But children these days they’ll just get better we are so much better at it all these days, so much better and then that’s it.....”

Yet there was within all the school staff that were interviewed a desire to understand more about asthma and ensure that they were following a policy. It would appear that if they had had a policy that said do this and then do that many staff would have appreciated this type of information....

13S:“But I think that’s why if we, you know kind of had a run-down available in the medical room, and you know in class handbooks, you know that would be very useful. I mean I would find it useful even though I’am quite confident.”

Another stated that this type of information would be useful if the member of staff did not have asthma....

12S: “yes particularly if the teacher hasn’t any experience of the.....and as you said it might be something they find they can’t relate to, or just....it’s outside their experience.”

Certainly asthma policies in school and the management of chronic ill health in the school environment are expected to be available (DSCF 2007).

Variation in knowledge and understanding regarding how medication works was a significant problem. All interviews that were conducted involved school personnel asking directly what a specific inhaler(s) was called, how it worked, what asthma was. School staff were often seizing the opportunity to acquire knowledge whilst they were giving information in the interview.

**6S: “It’s to do with the em....what’s it called? I can’t remember what it’s called”
[peak flow meter]**

11S: “is there a leaflet or something with this all...?”

9S: “what’s the difference in blue and brown [inhalers]...how do they work?”

In part this is human nature to acquire knowledge whilst the opportunity presented itself, however the nature and level of the questions and need to gain knowledge of quite a basic nature was surprising. First aiders asked what was the name of the blue pump [inhaler], how did it work, when should children use it? School meal assistants who manage children throughout lunch time were worried that perhaps children could use their inhalers too much, that they had seen inhalers that were

different colours and were confused about how the medication worked and what did they do?

7S: “you see, they they have bubbles and try and get them together but then what does that do?”

17S: “I’ve seen D----- with a white and blue twist,, and he uses it,, but I don’t know why and does it work..he seems ill with it.....”

9S: “Most.....I haven’tthere’s only.....when I said to you, G----- is a brown one and she had a diffuser.....is that it? A diffuser? [volumatic].

One senior member of staff in a school spent a significant amount of time discussing his own asthma, and asking all the questions that should have been addressed to someone within his general practice. This was not unusual; many staff who volunteered wanted to ask something specific concerning their own asthma.

6S: “I’ve had blue inhalers.... But now I’ve got brown...whats that for?”

15S: “My breathing gets bad in the Spring....I can’t go out on school trips then, is that right?”

Although these questions were not related to managing children’s asthma in school they were certainly indicative of the concerns and knowledge that school personnel had regarding asthma. Knowing how medication works, where it was kept and who had asthma were repeatedly commentated upon by all personnel.

Some school staff knew who had asthma in their class, many did not. Some had children’s inhalers that were labeled, and also with adjuncts that help children [volumatics, aerochambers] but others did not..

2S: “some teachers keep asthma inhalers in cupboards; some stuff has names on; some teachers know who’s asthmatic, some teachers don’t know who’s asthmatic.”

4:5.4 Situational Factors.

However, there was a difference between qualified teachers and classroom, meal time assistants. Those staff who oversaw children's lunch time play discussed their decision making regarding how they helped children with asthma whilst children were outside playing. Some lunch time assistants stated that they collected inhalers belonging to the 'worse' children and took them outside in a box to have near them, since the school office was too far away or locked at lunch time. They then mused upon the fact that they did not have all inhalers for all the children when directly asked and

13S: "you know....it's a long way to the school office...and we can't we can't use other's pumps....so so what would we do.....?"

Those school staff that oversaw lunchtime play with children discussed how they developed strategies to cope with children who become wheezy at lunch time; gathering together likely required inhalers is one, putting out benches for children to sit down on was another, ensuring that they had water for the children to drink, looking out for the worse children [in their opinion] to ensure that they knew where they were playing in case something went wrong. However, these lunch time assistants or school meal assistants [SMAs] when asked had they been informed who had asthma in school did not know, they had found out by observation, the children telling them or knowing the parents outside school. Often the SMA's knew more children with asthma than the school records revealed, since not all parents/ carers informed school personnel that their children had asthma. This was commented upon by several SMA's who said that they knew children X, Y, Z had asthma but that they also knew that the school didn't know which put them in a difficult situation.

9S: “ You see, I live next door to X----- and I know he has asthma bad in the nights you see, but I know that they [parents] don’t want the school to know, they just have to get on with it..... so I keep me eyes on them in case they get ill you know.....it’s like it’ll be the case mind, that he’ll get ill and the school, head won’t know what to do”.

This lack of freely occurring exchange of information regarding children’s well being reiterates the ‘them and us’ attitude and communication between parents/ carers and school commentated upon previously. A head teacher discussed how she would manage the situation where a child has an asthma attack but does not have their own inhaler with them.

1S: “Well you see if I thought there was a difference, and I have bent the rules, if I thought it was the difference.....if a child said to me I’ve a blue inhaler and I’m really struggling here and we’ve got one, to all intents and purposes if it’s the difference of managing that child’s asthma and sorting it out, I as a Head, I wouldn’t expect anybody else necessarily to take that risk, not risk, decision em.....but I would.”

Clearly stating in the quote above, that in her opinion this was a risky decision to take and as head she would make it but not expect anyone else in her school to make that decision. She indicated, along with many others in these interviews, the fear that in today’s society getting it wrong can lead to litigation and related consequences from the parents/ carers’ of the children. However, not acting can lead to severe and dramatic deterioration in children’s asthma and breathing (BTS/SIGN 2009).

4:5.5 Decision making and school asthma policies.

In order to cope with the day to day decision making regarding asthma management in school a series of coping mechanisms were adopted to allow school personnel to manage the situation. For example, not believing children when they state that they need their medication; little or poor communication between school staff and parents/carers' of children; not knowing where medication is kept in the school environment can be considered as coping mechanisms. Whilst these appear mal-adaptive coping mechanisms (as an outsider with experience in managing childhood asthma) they can be explained in the context that if children are disbelieved regarding their need for medication, then this negates the need to know where medication is kept and how children should use them. This then allowed individual school staff to maintain their *status quo* regarding asthma knowledge, management and how/ when to seek advice and support from colleagues. This ensured that their practice and knowledge was not questioned by others and their own decision making would continue as before.

None the less many staff felt that their current practice and knowledge concerning asthma and its management in school must change, reflecting that their insecurities and lack of confidence can lead to poor decision making that consequently influences children's well being. Throughout these interviews the staff reflected and consider their own knowledge and issues that influenced their decision making. They acknowledged that many of these issues were not satisfactory in their opinion and they would like to improve the situation.

For example,

15S: "We haven't had any training as such, have we really, so.....? I don't know whether that would come under the first aider or not you see, but then it would be nice for staff maybe to know that I think."

On the other hand, changing practice and understanding can be very difficult. One first aider who was expressly given the task of generating a school asthma policy discussed his frustrations concerning this task. The reasons why he felt that although the policy was written the school still had yet to adopt it and inform the decision making of the school personnel are shown below:

2S: “Well it was just a pointless exercise. Em...and I, in fact to the point where I would probably say if someone asked me to look at a policy again I would probably say I wouldn’t do it. It isn’t my job to implement it, it’s the governing bodies to adopt it and then to find a suitable way to implement it back, but I mean in general within this school, there does seem to be a lack of desire at this stage, to deal with some quite fundamental issues in terms around first aid, in general.”

This frustration with the school position regarding the implementation of a school asthma policy spilled over into other first aid situations that he dealt with.

2S: “You know, because I’m currently the only one in this school, that holds a First Aid Certificate, which I think is, well I know is wrong. There should be a number of us here.But there are....it’s not right, to me it’s not ...it doesn’t feel right that fact that I’m teaching and if there’s a first aid incident, who covers my class while I go and deal with it, it’s not right...it’s not enough.”

So without the full support of the school governing body it appeared difficult to implement policy and change practice, although this seems incongruous with the fact that the first aider was specifically asked to write a school asthma policy by the governing body. Being asked to undertake a task is not the same as being given full permission and authority to implement the task through to its logical conclusion.

Others also similarly comment upon their attempts to improve knowledge and asthma management in school.

6S: “I’ve tried to get the inhalers in the same place, in the top school so everyone can get them but its just too hard with no help.....I need help from ,, help from the head but its just too hard on my own.”

11S: “I know, I know ‘cos I have asthma how important it is to be calm but I can’t get others to understand it....who do I tell and when do I tell them. It’s Okay at lunch times, W---- and me we work together and I can keep her calm. But what about at the other times when we have problems in school... how do I tell others to stay calm.....I’m just a SMA [school meals assistant].”

It would appear that some school staff were keen to implement change and improve practice but even those that had the support formally given to them it was a difficult task, with no immediate reward or visible change. Discussing this issue revealed the same concern regarding as discussed before the need to avoid poor practice, and errors that can result in litigation.

2S: “There seems to be a bit of a lack of, of er....desire to spend that money, and it’sit’s not vast sums of money, but it certainly will be if there’s a law suit against the school.”

One school that appeared from the school personnel interviews to have a more inclusive and open communication with colleagues, children and parents/carers also did not have a detailed school asthma policy. However, it did have an unwritten accepted attitude towards the management of children’s asthma. This attitude towards partnership and working together stemmed from the head teacher and governing bodies that allowed staff time to discuss and evolve their practice.

9S: “And also if em they’ve had something at the weekend, parents will just come and say, watch out for.... Or come in that morning and say its really cold out, I’ve dosed them up but, for instance M---in particular because of its worse, significantly worse than the other children, we would go out and see Mum at the end of the day.....”

Adopting open communication concerning asthma, education and support for school personnel appeared to be very important. Working in this environment provoked more positive statements from school staff, however these staff still discussed the need for more knowledge and a consistent framework to operate in. Knowledge is accepted as being an important element informing decision making, the relationship between knowledge and decision making is discussed further.

Consistently school personnel failed to be certain of their own knowledge concerning the management children's asthma in school. Considering that the school staff volunteered to discuss asthma and its management in school, it is surprising that many did not feel that they knew enough about asthma and its management. Or during their interviews it became apparent that they did not know very much about asthma, for some reflecting upon their knowledge concerning asthma was a startling experience.

15S: "Yes I don't know why they're, if they are, somewhere centrally based. I mean I imagine if they are it's the first aid room.....yeah, but in year five some are in the cupboard, but I , I erm don't know where the others are.....you know I erm don't know I really don't know."

A first aider replied to the question do you know when you would call an ambulance?

6S "Probably after, probably after two or three, when one was.....about ten minutes maybe again. I don't know whether it's two or three times I can't, probably about three times, it depends on the child how.....I don't know do you know I don't know at all."

Consistently school staff appeared not to know:

- What asthma is;

13S: “I think its [asthma] a problem with the tubes, and it makes them [children] choke....”

11S: “I, I think it is hard you know to explain, its difficult but its when they can’t breathe in or is it to do with the heart beating too fast, I think it’s to do with the heart beating fast and that causes it you know....”

- how common medication works;

6S: “I think, I think the blue one is too strong, they don’t need it you know...its not good”

11S: “They don’t need medicines, they need to calm down and then they’ll be alright, mind I think its too much stuff that they take its too bad for them all the time”

- when it should be given;

8S: “er.....er, they take it at night, don’t need it in school, not required for school its only sometimes when needed” [ventoline].

- where medication is stored in the school environment;

15S: “it’s in the office, I think, the office its in the first aid room perhaps”

- whether or not children should be able to have easy access to their medication;

14S: “I don’t think they should have it, they shouldn’t have itexcept they could become bad perhaps if they have bad then they should have it, maybe...”

- and when to be concerned about a child sufficient to inform parents or ask for the aid of emergency care health professionals.

9S: “ I don’t think I would know, when should I call for help is it obvious, should I do it they should just calm down and wait and see.....”

Only one member of staff from 15 was quite clear about his understanding regarding asthma and what it was, how it affected children and how it could be managed.

This vagueness expressed by the remaining 14 concerning asthma and its management can be put into context. School staff are very busy, ascribed with the care and well being of all children in the school environment. The care of children with asthma is just one component of their role and thus they are expected not to be able to answer all questions, or be aware of the management of asthma as a parent of child with asthma might be. However, the vagueness concerning the use of medication, where it was stored and the children having access to their inhalers should not occur, these questions should be easily answerable by all school personnel.

In conclusion the lack of management and understanding of asthma in primary schools by school personnel appears to have common themes. These are discussed above and include lack of communication between school personnel, parents/ carers and school, support and education regarding the management of asthma is required and consistent support and recognition from all within school concerning the decision making that the each school personnel makes. The anxiety and isolation that school personnel feel when making their decisions is discussed as is the observation that many disbelieve children when they state that they need their inhalers.

One school only had staff that reported more positively concerning their communication and liaison with parents and children. All interviewed personnel asked for more information and education regarding asthma and its management and wanted a school asthma policy that they felt would support them in their decision making.

Some interviewees were more certain in their decision making and knowing why they did things and what the consequences were, one particular interviewee was very encouraging in respect to his decision making and care of children even though he had a difficult school environment to work in.

Considering in his words:

2S: “I think that’s....that’s I would say most people would assume asthma doesn’t kill. For something that’s not nice, its not a condition that you’d want, but its not a killer.... But I know it is. Probably I think if you worry about all of those things all the time you’d never do anything. And it certainly wouldn’t work in this environment.

To me.....err on the side of caution every time”.

Summarizing the themes discussed above it appeared that school staff had many comparable experiences across all seven schools. Many school staff reported that they found it difficult to manage asthma in school, that they feel isolated in their decision making and work in an atmosphere of at worst hostility between parents and school personnel and in the best situation (one school only) where communication occurred *ad hoc* but did occur between school staff and parents/carers.

School staff reported that their knowledge acquired outside school in other roles was essential for them in their decision making and management of children in school, that they had had little training given to them within school regarding asthma management and would like more. Worryingly some staff reported that they would not necessarily recognize when children had breathing problems (regardless of cause), and would not be confident in asking for additional advice from colleagues or emergency services.

One school appeared to have a different approach to their management of asthma, allowing children access to their inhalers easily, with staff reporting that they promoted an ethos of ‘respect and value’ within the school. The staff interviewed from this school reported that they felt that they did know some aspects of how medication worked but this was limited and would want to know more. In contrast another school had a first aider who was very knowledgeable about asthma and its management, but could not alter the way asthma was managed in school and attitudes towards school staff to asthma management and

problems with communication. School staff all asked for a school based asthma policy that would help them in their decision making and reduce their isolation concerning decision making and management of asthma.

The themes discussed above list the experiences of school staff in the management of child asthma. Most striking is the difference between staff who have taken the view to disbelieve children when they ask for their medication, in contrast to others who allow children access to their inhalers freely. Furthermore, this was re-enforced by staff describing their lack of knowledge concerning how asthma is managed, how medication works and where this is stored/ kept within the school environment. This variance was commented upon by children in this research.

These themes will be referred to further and placed in context of the child related data, research questions and established literature in chapter eight and nine of this thesis.

5: Review of School Asthma Policies.

5:1 Chapter overview.

The literature review has summarized the argument that local education authorities should in conjunction with each of their schools' have constructed school specific policies upon the management of chronic disease, including specifically within this policy or as a separate document the management of pupil asthma. Thus in the context of the research questions and the thesis title it is important to explore whether or not schools do have policies upon their management of asthma in the school context.

This chapter will present the methods used to ascertain if Bristol primary schools did have a pupil associated asthma management policy. Following this the results will be presented. Reviewing these results with reference to chapters four, six, seven and eight it is possible to understand if the existence of school asthma policies is an important factor in managing pupil asthma.

This chapter thus addresses the research question: what policies do schools have in place concerning the management of child asthma?

5:2 Method.

The city and county of Bristol had 117 schools in 2008 providing education for children aged four – eleven years. This number of schools

included infants, juniors and primary schools, both local education authority and privately run.

Using a survey approach was considered to be the most pragmatic method for gaining information regarding the existence of school asthma policies. Acknowledging that postal survey's can have a low response rate (Edwards *et al.* 2002), methods were put into place in order to maximise this response rate. This included enclosing a stamped addressed envelope included in the initial request, and two reminder letters to be sent at monthly intervals following the initial request. Please see Figure 13.

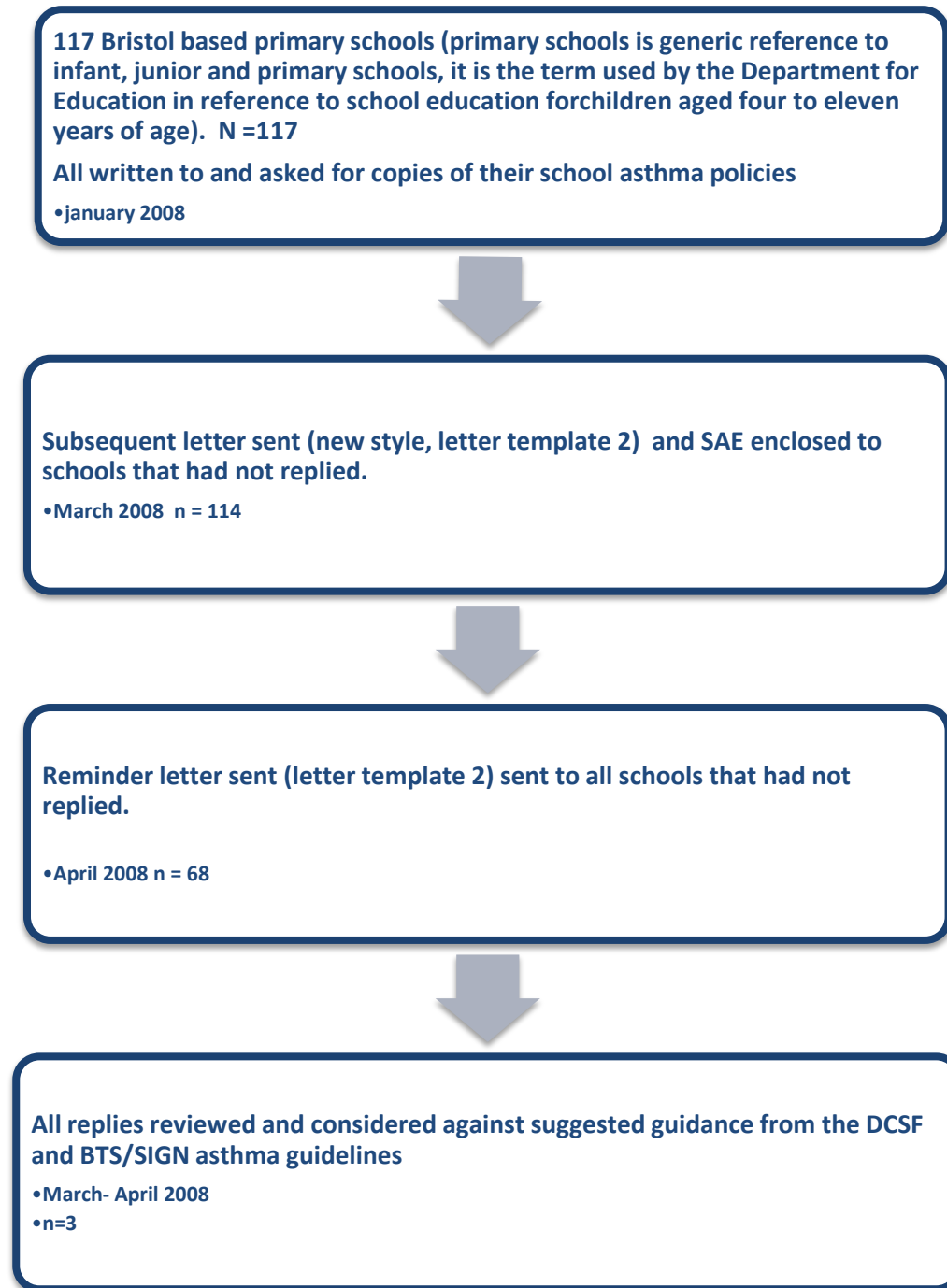


Figure 13: Process of obtaining school asthma policies.

The initial letter sent to the schools resulted in a low response rate, only three schools replied to this first letter. Since this was the initial contact with the schools in Bristol it was felt by the researcher to be very important to ensure that the tenor of this letter was such that it would encourage some schools to participate further in the research.

Consequently the letter was redrafted, including more specific detail relating to both the purpose of the research and how the information relating to their asthma policy would be used. This resulted in a significant increase in the response rate. This is referred to as letter template two in Figure 13, and table 1. In this letter reference was made specifically for copies of school asthma policies, but also school chronic disease ill health policies and medicine/ medication management policies since this is the area that often relates to the management of asthma in schools. They are often considered together by school staff in respect to the practical management of asthma.

Number of schools contacted	Date of contact	Type of contact	No. of responses	No. of school asthma policies returned	Other comments of note/ key information obtained.
117	January 2008	Postal request – initial letter asking for a copy of their school asthma policy* SAE enc.	3	0	None of the three schools that replied had a school asthma policy.
114	March 2008	Postal request- letter 2 sent asking for a copy of their school asthma policies* (reminder letter no.1)	46	1	22 schools replied that they did not have a school asthma policy but would now write one. The other 23 replies just stated that they had no school asthma policy.
68	April 2008	Copy of letter 2 re-sent & SAE (reminder letter no.2)	33	2	16 schools replied that they did not have an asthma policy and would now write one, the remaining 15 schools replied that they did not have a school asthma policy
TOTALS			82 (70 % response rate)	3	

Table 1: Summary of responses received to the postal survey asking schools for copies of their School asthma policies.

5:3 Results

Consequently from the initial 117 schools contacted in Bristol asking for a copy of their school asthma policy (if they had one), a reply was received from 82 schools. This is a 70% response rate. Only 2.5% of schools contacted returned a copy of their school asthma policy, as a percentage from all replies this is 3.7% of the schools that replied had a school asthma policy. In total 38 schools replied indicating that they did not have a school specific asthma policy, or a chronic ill health policy or medicines management policy but would write one now this had been brought to their attention. The same number of schools 38 replied indicating that they did not have a school asthma policy but included no further additional information.

Of the 82 schools in total that replied, three had a school asthma policy that they returned, 37 schools did not reply in any respect to this postal survey. The 70% response rate is a higher than average response rate to a postal survey (Edwards *et al.* 2002, Harrison and Cock 2004) which suggest that some of the caveats concerning recruitment and population bias may be less applicable to this research population. Although these concerns apply more readily to individual's response rate to postal survey's using questionnaires, a low response rate will induce population bias regardless.

Recruitment into phase two of this research relied upon having a high response rate to this postal survey, with schools indicating whether or not they wished to be included in the second phase of this research. Thus, attempting to maximise the response rate at this stage was a key requirement for the methods used in this postal survey.

Summary characteristics of the three school asthma policies received are presented in Table 2 (this is an extensive table spanning three

pages), against the key suggested content from the DCSF (2008), Asthma UK (2008) and BTS/SIGN (2008) asthma guidelines. Since 2008 was the year that this research was conducted, it is appropriate that the asthma policies received are compared against guidance available at that time. The three schools that replied are denoted in the Table as school A, school B and school C in order to differentiate them from schools subsequently participating in phase two of this research. Length of school asthma policies varied, school A's asthma policy was one paragraph and less than half a page of A4, school B's asthma policy was a few lines of text whereas school C's asthma policy was five typed sides of A4.

School C's asthma policy contained a detailed section which allowed the dates and times that the action had occurred to be inserted and signed off in the policy. Thus for example, one action within the school asthma policy was for the first aider to remove furry pets from the classrooms (pet fur is a known source of allergens inducing asthma in sensitive children); this action was dated and signed off by the first aider in the copy of the returned school asthma policy. School A and school B's asthma policies did not contain this sort of section.

Suggested key content for school asthma policies from combination of three sources, asthma UK, the DSCF and BTS/SIGN asthma guidelines.	School A	School B	School C
Whole school should recognise that asthma is a significant health issue for children.	Statement included that some children had asthma in the school.	Not discussed.	Statement included indicating that this was a whole school issue.
School should ensure that all children with asthma participate fully in school 'life'.	Not discussed.	Not discussed.	Not discussed
School staff should recognise that children with asthma should have immediate access to their medication. This should be facilitated in the school.	Asthma medication to be stored in child's classroom.	Not discussed.	A training package was drafted for INSET days (included in the returned information) by first aider but the school asthma policy indicated that this training day was not given. Asthma medication stored by school staff in classroom, or first aider's room.

Table 2: Comparison of received school asthma policies against best practice recommendations (this table is split over three pages).

Suggested key content for school asthma policies from combination of three sources, asthma UK, the DSCF and BTS/SIGN asthma guidelines.	School A	School B	School C
Keeps a record of children with asthma.	Not discussed.*	Not discussed.*	First aider had devised a system for recording children with asthma, but this was not implemented according to school asthma policy.*
Ensures that all staff are aware of what to do when children have an asthma attack.	Not discussed.	Not discussed.	First aider was identified as first point of contact.
Ensures that the school environment is favourable for those children with asthma.	Not discussed.	Not discussed.	First aider had identified this, for example reduced known allergens in the school, and removed furry animals from classrooms this action was documented in the school asthma policy.

Suggested key content for school asthma policies from combination of three sources, asthma UK, the DCSF and BTS/SIGN asthma guidelines.	School A	School B	School C
Has systems in place to reduce bullying that may occur towards children with asthma.	Not discussed.	Not discussed.	Not discussed
Ensures that all school pupils are aware of asthma.	Not discussed.	Not discussed.	First aider identified key assemblies when asthma could be discussed to pupils. However, these had yet to be given according to the asthma policy documentation.
Works collaboratively with health professionals, school governors, parents and carers and all interested parties to improve well being of children with asthma.	Not discussed.	Not discussed.	School asthma policy had been endorsed by school governors and school nurse, but not implemented in the school.

*denotes the acknowledgement that at the commencement of each school year parents/carers are asked to return forms to the school indicating amongst other factors any chronic ill health or medication that their child(ren) are taking. This should generate a list of those children with asthma, as well as other chronic health conditions. However, Asthma UK and DCSF state specifically that it should be asked directly: does your child have asthma? This table represents the key requirements of a school asthma policy from Asthma UK, BTS/SIGN asthma guidelines and the DCSF.

Table 2 indicates the suggested key contents for school asthma policies as suggested within BTS/SIGN asthma guidelines, asthma UK and

DCSF, this content is then examined for in all three school's asthma policies. The actual content, or an indication of the content of all three school's asthma policies is presented in Table 3. This allows the content as written by the respective schools to be considered upon its own merit and whether or not it contains useful information for the management of pupil asthma in school.

School A	School B	School C
<p>“Asthma affects children in school. Those children who have asthma should be able to access their medication at all times, this medicine should be stored in the child’s classroom drawers.”</p>	<p>“Children who have asthma attend this school, asthma is a cause of ill health and poor achievement.”</p>	<p>This was a five page typed document, with additional charts and sheets included that allowed record keeping and observation of when actions had occurred. The content of this policy was exhaustive and it is not possible to reproduce this in this thesis. From consideration of Table 2 the content of this policy can be seen to follow the key content as suggested by DCSF.</p>

Table 3: a summary of the actual content of the three school asthma policies received.

Additional information contained in School C's asthma policy related to checking medication to ensure it was in date. Also this policy identified the need to provide training for more first aiders within the school in the management of asthma, and practical issues pertinent to that school to improve children with asthma's well being and participation in school life.

These documents are summarized in Table 3 and provide information relating to the content of the three asthma policies received in this research. It appears that there is diversity in the type of information contained within the three school asthma policies received. Two policies were very brief in content and did not contain sufficient information to address the key suggested requirements (as discussed), one policy did address the key requirements.

From the 82 replies to the request for a copy of their school asthma policies, 79 schools did not have a written policy. Two schools had a policy that acknowledged asthma was a health problem for children and one of these stated that children should have access to their medication; the third asthma policy was comprehensive in its detail and guidance but was not operational in the school for reasons not discussed in the copy of the school asthma policy.

In conclusion with reference to the research question what policies do schools have in place concerning the management of child asthma? This research has generated the answer that most Bristol Primary schools did not have any written asthma policies, the three that that did were variable in content, two lacked a sufficient level of detail and the third was well designed according to suggested guidance but not used by the school. These will then be discussed further in subsequent chapters of this thesis, including the discussion chapter to gain an understanding of what it is like to manage asthma in a school environment.

6: Children's experiences of asthma in school.

6:1 Chapter outline.

This section will discuss the qualitative data gathered from the children who were research participants (see section 3.6.8 for children's inclusion and selection criteria) in seven schools. These are the schools for which there is both qualitative and quantitative data gathered. There is presented a précis of the methodology underpinning the method utilized to gather the data and reference to appropriate references when required. This discusses using interactive methods of inquiry with children, in this case art work, their ability to engage with the research task and consideration of the principles of ethical research practice.

Following this the method will be presented and then the research findings. A full and detailed discussion, synthesis and analysis of all the relevant data in the context of the research questions will be presented later in this thesis in chapters eight and chapter nine.

6:2 Methodology.

6:2.1 Involving children in research.

A similar argument for the adoption of qualitative research methods of inquiry as discussed in section 4.2 holds for this phase of the research.

This relates purely to the decision to utilize interviews and children's discussion of their experiences of asthma in school, how this data was analyzed and the production of findings. This can be reviewed in sections 4:2 -4:3.1. However, the additional research methods used and adoption of alternative mediums of gathering research data will be discussed below.

Working with children requires acknowledgment that children can present methodological challenges. These are varied and rest within the methodological assumptions inherent within research methodologies as succinctly reviewed by Coad and Lewis (2004). These limitations associated with research methodologies include for example the unequal power relationships between adults and children, and children understanding that there are implicit boundaries to the relationship that limit their participation (Twycross 2009, Coad and Lewis 2004). These methodological issues need to be considered together with the practical considerations associated with the limitation of children's attention span (which is assumed to be less than adults and varies with age and gender in primary school children); engagement with tasks (Bee and Boyd 2006) and the ethical principles associated with researching with children (vulnerable subjects) alongside the ethical considerations *per se* associated with conducting research (Twycross 2009) see sections 3:8.2.

Reviewing the methodological assumptions inherent within researching with children perhaps the most important is the consideration of how these assumptions affect the analysis of the research (Coad and Lewis 2004). This is as a consequence of the marginal position children hold in relation to adults (Christensen and James 2000, Lewis and Lindsay 2000) and the nature of the power relations that discourse has when occurring between adults and children (Lewis *et al.* 2003, Clark and Moss 2001, Woodhead and Faulker 2000). However, Coad *et al.* (2009)

summarize how in the last decade emphasis has now been placed upon actively involving, gaining participation and consultation of children in research (DH 2004, Department for Education and Skills 2003).

Christensen and James (2000, page 7) state that

“For participation to be effective and sustainable there also needs to be concomitant move to participatory methods that are specifically devised to engage children.”

Adopting both involving and participatory methodologies in exploring and understanding children’s perspectives in childhood studies has become a much more commonly accepted approach in the last decade (Coad *et al.* 2009, Twycross 2009) since its early exploration by Christensen and James (2000). Advocating that this approach helps reduce some of the power imbalances associated with child (researched) and adult (researcher) relationship (Christensen and James 2000, Coad *et al.* 2009). Participatory methods of inquiry are known to help participants (children) with the sharing of sensitive information and allow children to use methods that are meaningful to them (Coad and Houston 2007, Willow 2002, Lewis and Lindsay 2000, Kirby *et al.* 2003). However, involving children with the research task and allowing them to be engaged in activities to establish a dialogue with the researcher can be just as useful and rewarding (Darbyshire, MacDougal and Schiller 2005). Whilst this is not participatory at the maximum level as suggested by Hart (1992), the significance of involving children in the research methodology and that they have been given permission to freely engage in the activity at whatever level they wish can allow insight into their world as reliable as that of the maximum participation as suggested by Hart (Fargus-Malet *et al.* 2010, Coyne 2009).

Utilization of art based activities is frequently used to assist with children's participation (Coad *et al.* 2009, Coad 2007, Darbyshire, MacDougal and Schiller 2005). Art is seen as an accessible method for allowing children across a large age gap and abilities to participate and express their views. Choice of an art based activity can be challenging as stated by Pink (2001) since images are personal and permeate work, lives, conversations and dreams (Coad 2009). Art based activities are diverse and include as listed by Coad (2009) page 58:

"Paintings, drawings, photographs, graffiti walls, collages, mapping, textiles, clay, woodwork and scrapbooks."

Mauther (1997 Page 23) states that all children including those who are not literate, or have language barriers appear to

"enjoy the spontaneity of using art-base techniques as they can provide child-centred structure to enable them to describe their views, environments and worlds in a way that is meaningful to them."

Both Kirby *et al.* (2003) and Hill *et al.* (2004) state that all children appear to enjoy this activity whatever their age, and even those who find it difficult to convey their feelings such as adolescents and very young children can participate well in art based activities to express their opinions. It should be noted at this point that the utilization of art based methods of inquiry is not limited to research with children, but is widely accepted as a method of inquiry into perception, values and experiences of adults (Holloway and Jefferson 2000). It is now a powerful tool to involve adults in diverse activities such as engaging with change in complex organizations (Martin 2003); who states that generating employee's thoughts and views about change can be gathered by examining, exploring and analyzing their drawings upon the topic

"If, however, everyone is to be involved, both the drawing of the picture and the analysis have to be carefully facilitated so that individuals do not feel isolated and devolved of power" (Martin 2003 Page 119)

Coad *et al.* (2009 page 59) suggest that the consideration of all the above points allow utilization of an arts-based activity to assist with interviews (the process) or in a research based conversation can help a child feel relaxed and provide a diversionary, legitimate activity. In healthcare research, these activities are rarely used in isolation (Coad 2007), but support other data collection techniques such as interviews.

Although the decision to utilize art activities in this research was taken nearly two years prior to Coad *et al.*'s (2009) paper, the rationale presented by Coad *et al.* illustrated in the quote above succinctly summarizes why this decision was made and how the art based activity was used, to support interviews. Coad *et al.* (2009) state that art based activities need to be focused in purpose, used judiciously at appropriate stages in the interview and

“whilst they might appear fun and spontaneous to the children, in reality, they are thought out and thoroughly prepared for during the study planning.” Page 59.

Interpretation of the art produced by the children rested entirely upon observing the image and asking the children to describe what the picture represented, and notes taken at the time the image was created. This can be criticized by psychosocial researchers who believe that the image created can be dissected further and represents a diverse reality (Hollway and Jefferson 2008). Furthermore, the analysis of images and their interpretation is explored in detail in other research paradigms such as using photographic images in ethnographic research and social anthropology (Emmison in Silverman 2004).

However, for the purpose of this enquiry, accepting that the picture represents whatever the child states it does, allows many of the principles discussed as important characteristics of involving children in

research to be demonstrated. Such as a more equal power relationship, the children are not questioned in their belief and stance exploring their picture. Whatever the child believes about the topic is also permissible and their generation of a valuable piece of art has been recognized in the research environment. The principle was to ensure that they (children) were involved in the analysis of the picture as it represents whatever the children state it does. This principle is suggested by Martin (2003) in her consideration of good practice (although in relation to adults) as important in the interpretation of artwork and that it was crucial to involve the artist (creator of the artwork) in the analysis and interpretation of the work.

Thus in this research children were fully involved in the generation of the research data, their involvement was maximized at all times and the children owned their artwork in its entirety with the researcher accepting that the picture represented whatever the children stated it did. Using art as a means to discuss asthma and children's experiences in school was an attempt to reduce the unequal power relationships inherent between adults and children and give permission for children to talk and discuss their experiences freely.

Consideration of how children can perceive their own health, emotional intelligence, their ability to understand their own feelings is briefly summarized here. Harris (1994) stated that children of school age are able to grasp the relationship between beliefs, desires and emotion and relate this to their own health. Interestingly, Hubbard and Coie (1999) suggest that children aged four to ten years old begin to see themselves as social beings, that they come to understand that their emotional state is influenced by others. Harris (1994) supports this further by stating that children in this age range can interpret their reality further by understanding consequences of behaviour and the social requirements of their societal context. Consequently children are capable of feeling

pride when they have done something well resulting in eliciting approval from others, or shame if the converse is true. Thus it is expected that the children in this research are able to identify their thoughts and feelings, relate this to their understanding and experience of asthma in the school setting and interpret the consequences of having the disease upon their own social interactions and peer friendships.

6:2.2 Recruitment and selection of research participants.

Please refer to sections 3:6.5- 3:6.8 for a detailed discussion of the process of recruitment and selection. The following section will explore the fine detail that is required in order to assimilate how the research findings presented in this chapter represent the children participating in this research.

All schools that had agreed to participant in the research (eleven schools in total, seven are considered further in this thesis as discussed in chapter three) were asked to identify children that met the research inclusion criteria. This inclusion criteria was that the school was informed and aware that the children had asthma and that this was documented on the school held child records. Following the identification of these children, the school gave each child the information sheets and consent forms (see appendix iii). Consent to participate was sought from both parents/carers and children. The information sheets give contact details of both the school contact person and the researcher. Completed consent forms were returned to school and then collected by the researcher. Only those consent forms that indicated agreement to participant in the research study were given to the researcher. Records were kept as to the number of children approached, how many gave consent to participate and how many declined (see Figure 3.9).

At this point the children who had agreed to participate were known to the researcher, children's names were used by the researcher in all interactions with the children; but each child was given a unique identifier number and this number is how the children are referred to in this thesis. Maintaining children's anonymity is of primary importance and the responsibility of the researcher. In total from all eleven schools 196 children agreed to participate in this research, (total number of children upon school rolls in all eleven schools 1129).

The data presented below reflects only the qualitative data obtained from schools in which there was also quantitative data available (N=138). Thus this excludes the children under the age of seven years. However, these children did provide useful qualitative data and upon consideration of the themes arising in this research the themes from younger children (infant aged) did not add any differing or distinct themes that were not covered by the seven schools discussed in this thesis. However, the decision to research with these children was made to ensure that the experiences of younger children would be considered and if they were differing from older children these themes would have been discussed.

6:2.3 Method of data collection.

Schools were contacted to ascertain a suitable date, time and venue to undertake this research with the research participants (children). For some schools this was one or two whole days, for others it was a series of half days. Schools were asked to identify groups of children who could work together within the research participants from their schools, with each group having between four and eight children in total. In some cases this worked well, and schools constructed groups that were of a suitable size, with children who were of similar ages however, in some cases schools had not been able to construct suitable sized

groups and the largest group of children that was involved in the research was 16. The larger groups did reduce the quality of the research data that was gained from the research respondents since groups of this size required some directional interaction by the researcher to maintain good dynamics and well being of the children.

None the less, in all cases research data was gained from all the research participants and in no cases were the children placed in situations in which their well being was affected or reduced since the researcher is also a qualified and licensed teacher. Thus the researcher had a professional obligation to ensure that both the research ethics were upheld and the statutory obligations of the school were carried out in respect to children's well being and safety. However, this should not negate the observation that the larger groups of children produced challenges to the research method of data collection and required the researcher to be responsive and flexible in the dynamics of working within schools and the research led objectives and principles.

Research data collection with the research groups of children occurred within a suitable location within the school; this was at times problematic since most schools have every expanse of their school utilized for teaching. Thus the research data collection was undertaken in rooms/ areas that did not necessarily have all the key characteristics that were asked for such as space, privacy, quietness, since it was impossible for schools to provide a venue meeting all these criteria. For example, in some schools the school library was used or the medical room (which would have occasional use during the research by school personnel). Inherently though the researcher ensured that the research was conducted in a space that was generally suitable for the task, that health and safety was maintained and that the children could work without interruption.

Prior to data collection with the research participants the room/ space was set up by the researcher with all the art equipment laid out and the digital recorder set up. The art equipment that the children could utilize included a variety of sizes and colours of paper/ card, pencils, pens, felt tips, paints, glue, stickers, sparkles, items to stick on paper such as fluffy pom poms, pipe cleaners, straw, wood, lollipop sticks, silver paper, and much more.

Gaining the cooperation of the children, their interest and confirming assent for their participation with this stage of data collection involved explaining to each group who I was, why they were there, reminding them of the research information sheet and their consent. No child at this point expressed a wish not to participate in the research. Ongoing assent in the data collection phase was also expressed by the children volunteering information and discussing their thoughts freely. However, some children participated more fully in this research than others, and some children spoke and participated freely but at times chose to be quiet. In all cases each child's wish to participate and involvement level was accepted and not challenged. All interactions with the children were digitally recorded and this included the explanation of the research as listed above and the conclusion and thanks for participation at the end of the research data collection. Please see appendix vi for the structure followed in the interview and art work phase of data collection with the children.

In order to help generate discussion, develop a rapport with the children and actively engage in dialogue with the children the researcher read a story to the children, this was always the same story "The Three Little Pigs", it was chosen since it would appeal across the whole age range of research participants. The younger children would be confident in their understanding of the story and the older children would be able to reflect more critically upon the pictures and their importance to the story

as well as appreciate the rhyming text that the book was written in. Furthermore, this book was a 'pop up' book and the graphical representation that the 'pop up' pictures brought to the story caused the children to discuss and reflect upon the power of pictures. Thus this helped with setting the scene for the research task ahead.

Once the story was completed the pictures and choice of the book was discussed, with the children often stating that because the wolf 'huffed and puffed' perhaps he had asthma. They then discussed how the pictures helped them understand the story and added a lot more information that they found useful. In generating their art work the children talked freely about their asthma and this conversation was digitally recorded as well as each child discussing their pictures as they were finished.

At times the researcher had to give the children some help with spellings (but only when asked), or explain the questions more fully to groups of children but essentially the children were in control of the discussion. Each piece of art work that was generated was digitally photographed (with the child's unique identification number recorded upon it) and the child was able to take home their art work at the end of the school day.

Thus the following types of data are generated from this: the recorded discussions with the children, the art work that the children generated and the researcher's field notes. Subsequent to the data collection the research participants were sent formal 'thank you letters' upon headed university paper which included a summary of what they said their pictures were about thus making the letters unique.

6:2.4 Method of data analysis.

The analysis of the children's discussions and interviews followed that as discussed in section 4:3.3. In summary this involved thematic coding

throughout each transcript and then similar themes were linked together and subsequently discussed.

The analysis of the children's art work involved considering the child's explanation (transcribed from the digital recording) about their picture compared with and against the digital photograph of their art work. In some cases several pieces of art work were generated by the same child and these were all considered at the time of generation by the researcher and the child and discussed as above. Further analysis could have been undertaken exploring the ways in which children create works of art, for example in psychological literature (Gardner 1990) which discusses why different children operate in different ways in their creating of work and perceptual understanding (Tickle 1996). However, this was not noted at the time of the data collection since it was not considered to be of particular relevance in order to answer the research questions.

However, the impact of the children's art work is considered in the data analysis when the child discusses how their art work made them feel, what it is 'saying' to them and the reaction to the picture from others in the group. This was considered appropriate since this ability is anchored in educational requirements from 1991. The following has been an underlying tenet in the construction of educational provision for children aged five and above:

Pupils should become visually perceptive, develop powers of observation, and be capable of selecting, interpreting and recording what they see, think, feel, and know, using art media.

DES (1991): para. 4.5.

This was considered appropriate since some of the themes that become apparent in the section below relate to feeling different from peers, this was often portrayed in the pictures that the children drew.

Consequently, reviewing what the children said about their pictures and

how the pictures made them and others feel in the group was considered important in order to address the overall research question: what are the experiences of managing asthma in school?

The following presents a summary of the main themes presented from analysis of the data obtained from the children and interspaced appropriately with digital images, and discussion of the impact and meaning of these images.

6:3 Findings.

The following themes are apparent in consideration of the research data and will be discussed further including reference to the art work that the children generated. Figure 14 summarizes the key themes that will be discussed in this section, the Figure illustrates how having asthma surrounds the children in every interaction or consideration that they make in school. The concept of a circle with key themes interspaced is an attempt to visualize how all these themes interrelate.

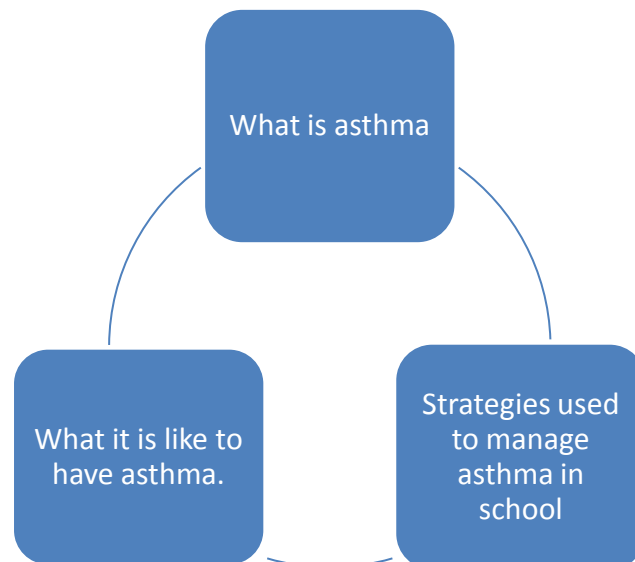


Figure 14: the key findings from the children's perspectives.

These main theme headings are subdivided into:

- What is asthma:
 - an external illness
 - an internal illness.
- Strategies used to manage asthma in school:
 - physical strategies
 - emotional strategies
 - telling an adult – making the decision who to tell and why.
- What it is like to have asthma:
 - ‘Good’ feelings
 - ‘Bad’ feelings.

Consequently the following discussion will commence with the first theme, what is asthma, then the strategies used to manage asthma and finally how it feels to have asthma.

6:3.1 What is asthma?

A few children expressed some concern that they did not have asthma in their opinion, but that their parents, the school and their doctor thought that they did. For them describing asthma was something that they could do and they wanted to be in the research (this was confirmed once again expressly at the time that this point arose in the conversation), but that they didn’t consider that they themselves had asthma. One child described some of the symptoms of asthma but denied that he had had any of the symptoms however, occasionally he needed to use a nebulizer (an indication of quite severe asthma).

⁷627: Miss I don't have asthma.

CF: You don't have asthma, does your Mum and Dad think you have asthma?

627: Yes, and the school and the hospital but I don't have it.

You see asthma is something that makes you bad, and your breathing and you see well, well like that's it. I don't have it at all.

..... sometimes I get a bit short you know, and then I need my nebulizer thing but most of the time I'm all right...I don't have asthma.

6:3.1i An internal illness.

Another group of children responded to the question what is asthma as below:

⁸37: It is just something that you get naturally and you have it no matter what it sometimes comes on unexpectedly and it is a bit like something creeping up upon you.

26: It is a horrible thing that I wish I wasn't born with.....

.....yes it is a bit better now when I was younger I had to go into hospital with my Mum and have oxygen and breathing stuff with tubes it was really bad.....really bad.....

Older children referred to asthma as below

⁹100: asthma is when it gets hard to breathe and you can't do anything.. its typical and gets me....

Yeh it gets me all the times.

856: you see it's the veins, the veins don't get the oxygen and it's the air it's the air we breath and that's it you see its this and we push it around and its ok when its outside but whens it inside that's when it gets bad (see Figure 15)

....it gets bad and that's it cause it's the veins and that's how we get it.

⁷ Child aged 8 school 5

⁸ Children aged 7 and 8 school 2

⁹ Children aged 10 school 4

This was a detailed attempt at an explanation concerning what asthma is made by a ten year old girl.



Figure 15: 'what asthma is' drawn by a 10 year old girl.

Other children talked about asthma in not as much detail or such detailed terms. However, many of them agreed that it was something inside them not outside their bodies.

¹⁰**643: its red breath, its breath and when its red that's when my asthma is bad.**

CF: why is it bad?

643: its bad cause it hurts and that's it that's why and its red.

Other children realized that it is something to do with their 'insides' but could not articulate it as well.

¹¹**220: you see its inside me, its all gone to jelly and wobble and that's what asthma is and then when I breathe it out it comes out as bad breath and jelly**

It hurts and it makes it bad for me (see picture -Figure 16 drawn by this child)

¹⁰ Child aged 7 school 7

¹¹ Child aged 8 school 3

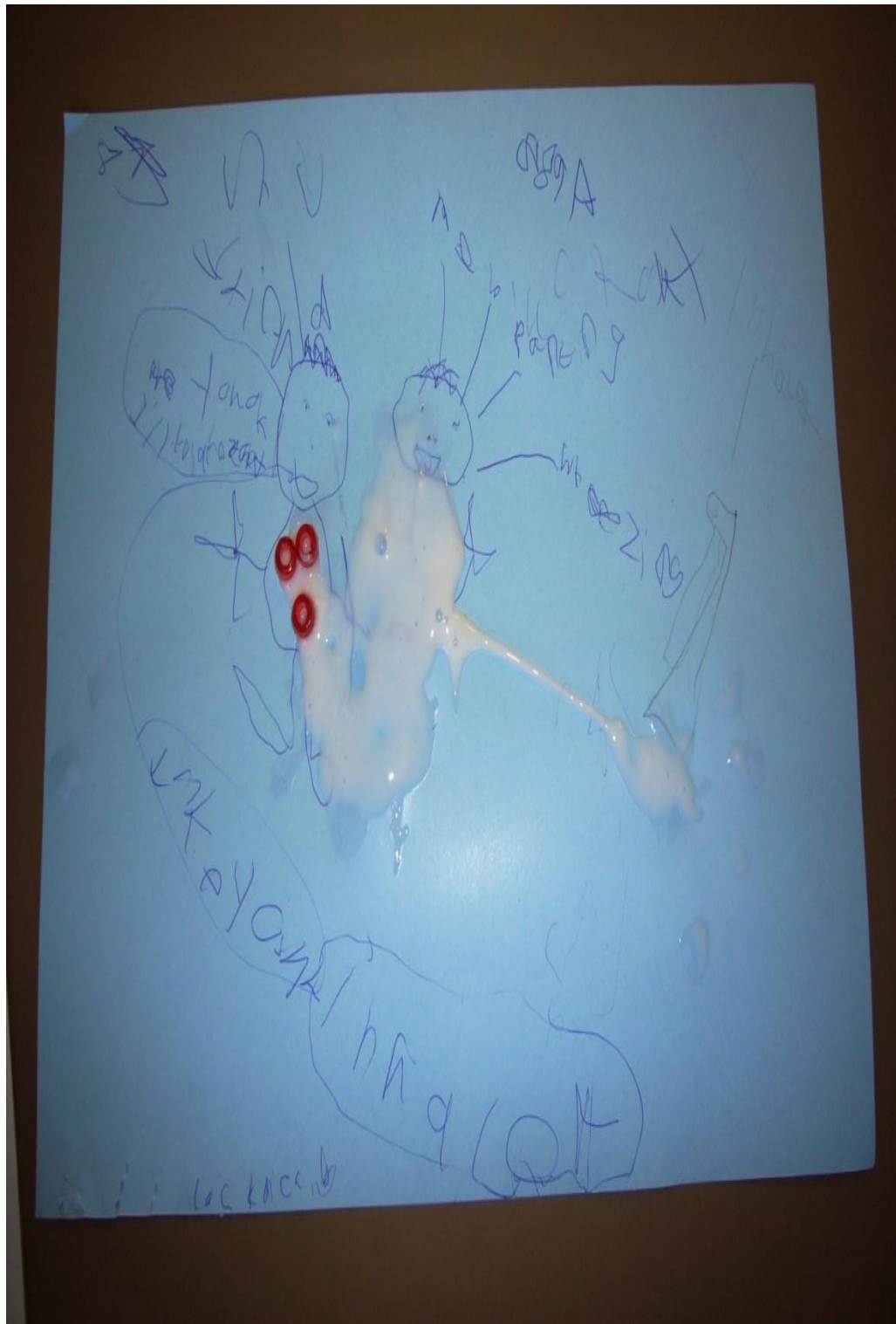


Figure 16: Asthma is when 'the insides are jelly and wobble with asthma'.

6:3.1ii An external illness.

Some children discussed asthma as something that was outside them, and not related to their bodies. These children were from a range of ages and schools, describing asthma as when they were stopped from doing something by the air/sky, or it was their friends that stopped them. For example

¹²717 When the sky stops me and I know that's what it is the sky gets too together and that stops me from doing it, I can't get through the sky it's too close and that's what asthma is.

'cos its too close getting through it is not good and it makes my breathing bad and thats what asthma is.

521 When it gets bad when it gets bad is when I can't do it....its because they are too close and I can't get through or they stop me.....

CF 'they'?

521 yep zzzz and qqqq, www [friends] they get close and I can't get through so that is what stops me.....thats what it is my asthma is from my friends and they they cause it its from them.....then 'cos they stop me then the breathing is bad.

This example illustrates how some children thought that asthma was a consequence of how outside things caused the children to have the symptoms of what they know as asthma. That it was the outside factors stopped them from breathing well and this they knew to be asthma.

6:3.2 Strategies used by children to manage asthma in school.

These could be divided into physical strategies/ activities that they have adopted and emotional strategies that they had to help them manage their asthma.

¹² Children aged 8 and 10 school 3

6:3.2i Physical strategies.

Physical strategies included having a rest or sitting down when they had an asthma attack.

¹³**666: I sit down, 'cos when its bad I sit down and get my breath.**

999: yeh, but if you are out [outside school buildings playing in the playground] you can't get back in so it is hard to sit down, sometimes you have to stand up and that's bad.

Sitting down was cited frequently throughout this research as being important in order to help manage their asthma. Some schools according to the children did not allow or facilitate sitting down unless it was associated with another task such as having a drink of water.

¹⁴**1001: You see, if its for a drink then that's all right, you can sit down then but not else.**

165: I get a drink but not in a glass I use the water fountain but then I lean against the wall and then that's OK.

One school appeared to have a different philosophy regarding allowing the children to sit down and get their breath.

¹⁵**725: I am trying to draw the quiet area and me sitting down on a bench to try and show that I am resting.**

888: I can sit down whenever, not just in the quiet area I can sit down in the class room, or in the gym.

This school seemed to promote the activities that the children stated they found helpful for their management of their asthma.

Other physical coping strategies involved avoiding trigger factors that the children knew caused their asthma to become worse.

¹³ Children aged 7 school 6

¹⁴ Children aged 8 school 1

¹⁵ Children aged 7-8 school 7

¹⁶222: Well I have to go outside and then inside in plants yes it's the hayfever or pollen that's the problem. So I have to walk away or avoid the plants or go in and out.

77: Yes I have to do the plants and avoid them like my friend.

867: Yeh I get that and I do have to go in and out and stop playing.

Many children discussed how they had to avoid playing outside when pollen counts were high and triggered their asthma and hayfever.

Similarly, children discussed how they reduced their physical activities when in school so that they did not have an asthma attack.

¹⁷22: I just run slower, I can be really fast but then I just have to run slower so I don't get it [asthma] you see.....so I can be the fastest but I'm not ever, ever first and I know I could be...I'm really fast but I can't do it.

¹⁸132: I don't run slow, I don't do it you see I know it's bad for me asthma so I don't bother it anymore [school gym lessons] I just sit and watch and they let me.

¹⁹466: I don't ***** [expletive removed] do me sports, I just spend the time looking at it all, I kick the ball back if it comes off but I know especially when its hot that I can't do it so I don't. No one cares...they all laugh at me so I bloody well just watch it's easier.

11: I walk across the playground slow, I tend to sit quiet and then I walk slow when I have to go across to get to I.T. then I leave at the start of play so I can get there all right and not be breathless.

Another child in a school which had three stories within it discussed how she asked to move tutor groups so she would not have to go up and down the stairs to the top, claiming that it made her asthma bad.

²⁰333: you see, I had Mrs X---- she was on the top and I really liked her, I had my friend X--- and we were really cool but then I couldn't do..... and get my breath it was all too much and I had to, well I couldn't so I asked to move. I now have Mr P---, he's alright but my friend X---- is in the same class still and I miss her.

Such drastic measures are not frequently mentioned but children did discuss how they planed getting across school sites in ample time and

¹⁶ Children aged 7-9 school 6

¹⁷ Child aged 11 school 4

¹⁸ Child aged 9 school 3

¹⁹ Children aged 10 school 1

²⁰ Child aged 8 school 2

'good breath' to borrow the words of a child aged seven (from school 7) to enjoy the lesson. Considering that the school sites are not as vast as secondary schools this is a noteworthy effect.

Many children described how physical activities were curtailed by their asthma. There is a clear distinction here between the physical coping strategies that children adopted to avoid having their asthma become a problem in school, and the consequences of participating in school activities which provoked an attack and the children discussed these quite differently. The latter will be explored later.

6:3.2ii Physical strategies used to cope with an asthma attack.

When children had an asthma attack (what they called an asthma attack, which may be different to a medical definition but the children's words understanding will be accepted here) they described how they coped with it in matter of fact terms.

²¹7: I just sit down and wait, My Mum helps me [Mum is school meal assistant]....she gets me better.

15: When it gets bad, I just stop and think and calm down. 'Calm down' I say in my head and it helps me, you see I know it does calming down but its hard when you can't breath any better.

723: I stop, sit down and go quiet and then wait it helps to wait and then it might get better.....if it doesn't then I sort it out with everything else I do I just sort it out further and along the lines of being better....my dad he says it takes lines and lines of thinks that , yeh that's it he thinks it out in lines and that helps.....

CF What's lines?

723: that's how you think of it lines and then they get shorter and you can breath better.

²¹ Children aged 8-9 school 5

Interestingly, only some children referred to using their inhalers to help them when they had an asthma attack. Often in a matter of fact approach, then discussing other physical strategies that they had developed to help them cope with their asthma.

²²12: OK I use my inhaler.

29: Once I have had to use my inhaler, if I need to use it two times then you can go and phone my Dad and he will come and collect me.

330: I take mine before I do rugby.

623: I take mine before I do swimming since I got so poorly swimming I couldn't catch my breath.

220: Inhalers help your asthma.

6:3.2iii Physical strategies used to prevent an asthma attack in school.

Other children discussed how they managed their asthma and got things sorted out by discussing their strategies that they had adopted in order to reduce their asthma in school, or their need for help.

²³620: you see, 'cos I know that it's bad when I go up the stairs I make sure that I take the inhalers with me and I puff on them quick like in the loo when no one is looking...then I've got the puff to go up the stairs and I can do it then...

300: gosh yes that's a good idea...I've never done that I'm going to do that as well it will help me too.

245: yes you see that's good, I take my time and ask my mum to give me my inhaler just as I go in the door and have it ready for when I come out 'cos I know I'll need it then....she always brings it with her and I use it then.

Another group of children discussed similar methods of managing their asthma...

²² Children aged 7 school 7

²³ Children aged 10-11 school 2

²⁴723....yes, they are and they can be helpful [school meal assistants] but not when you are really ill and can't do it and walk.....then its good cause I have my inhaler in my pocket.....

(Cries of exclamation from others in room)

423: You shouldn't have that!

723: Yeh...my mum says I have to have it cause I get so ill and its helpful....thats what I like having my inhaler with me.....

CF...How do you feel about that?

723: Well I keep it quiet and use it like.....

This type of method for managing asthma was not uncommon, many children discussed having their medication with them but not telling the school, or utilizing ways of reducing their likelihood of having an asthma attack.

Children discussed whether or not they had their inhalers in school and this in itself caused some confusion. Within the same interview

²⁵1: Yes I have my inhaler in school.. we all do....

7: No we don't I don't have my inhaler in school, we're not allowed to bring it in...your wrong...

1: yes I do we have it in the office...

9; no it isn't it's in the class room and I have mine I think in the classroom.

15; No we don't we don't have it in school its not to be in with us and instead we have to wait until we get home..

1: you're wrong its in school with us....I have mine.

In another interview similar confusing points of view were expressed,

²⁶45: Yes you see its like this we have it with us and its in the office I think...

²⁴ Children aged 7-9 school 7

²⁵ Children aged 9-11 school 5

76; not it isn't its in the staff room and you have to knock on the door with it and that's it that's where it is..

88a: no you sees it isn't mind in the school we can't bring it in with us.

One school had within it a consensus of opinion about what and where their inhalers were.

²⁷156:yes you see we can all have our inhalers in school with us, and they are in the classroom in our drawers and then we get them anytime that we need...

222: yes that's right they are in the classroom and then we can get them whenever we need them and that's good.. its easy.

6:3.2iv Emotional strategies used to cope with asthma.

Children handled emotional consequences of having asthma in a number of ways. They felt that the understanding and support of their friends was very important and wanted to be included in friendship groups. Consequently they tended to tell some of their friends that they had asthma (often these were children who also had asthma) and not discuss this with other friends who did not have asthma.

The following extract from an interview in school two summarizes how some children told their friends that they have asthma, and why they thought it was important that they told them.

CF: you are drawing your friends do they know you have asthma?

²⁶ Children aged 7-9 school 6

²⁷ Children aged 8 and 9 school 7

²⁸423: No

CF: Do you tell your friends 423?

17: most of my friends in my class know that I have asthma.

72: I give them a warning that it may get bad, just give them a little warning.

423: I Think my friends know already

72: I yes, most of my friends know I think so.

CF: is it important that your classmates know?

423: I think that sometimes it is because especially your other classmates because I used to have my inhaler often, it helps a lot. But now I don't need to use it that often so it isn't so important.

However, other children stated that they only told their friends who have asthma since they only would understand.

²⁹490: I tell those who have asthma themselves, we know what its like and have the same things I don't want the others to know and they don't understand.

662: I just tell my friends only with asthma, everyone here has it and knows whats it like, mind you need to understand that and have it yourself otherwise it isn't good...you see only those of us who have it only we need to see how it is and then get it sorted.....that's why I tell my friends with asthma they know how it is.

945: yep that's what I'll do as well mind, you see only me mates who are bad with asthma know what it is like and I only tell them you see so we get on with it then, it'll be well you know we get on with it and then they help 'cos they understand it like and that is important.

It would appear in both circumstances what was helpful to children with asthma was having their friends understand it. Friends who were supportive and helpful were considered to be most important and these helped children manage their asthma. Those friends that did not understand about asthma could have actions that are more upsetting to

²⁸ Children aged 10-11 school 2

²⁹ Children aged 9-10 school 4

children with asthma, for example staring at them when they needed to use their inhalers.

Examples of how children who did not understand and are not helpful to those with asthma are discussed below in the following extract.

³⁰**612: M stares at me so I just need to get on with it and do it quickly [take inhaler]**

CF: so staring is that helpful or not helpful?

612: I don't like it because I am not the only one with asthmaand....has it. I have the badest asthma in my class so they really know that I have asthma.

341: Some people understand more, it is hard to understand if you don't have asthma. Staring doesn't help and makes it go wrong, there is no where to go and get space.

In another extract from a transcript in one school others discussed staring in similar words.

³¹**525: Its not really bad but people look at me and its really embarrassing when people look at me I don't like it.**

310: I hate it people looking at me.

250: yeh.

620: When I take my inhaler my best friend is always there. And he "like says what...so your going to use your inhaler??" And I don't like it. So I don't use it.....

Sometimes you have still quite a lot when you can't breath, and you can't help it all and you can't use your inhaler cause, mind, its like this daps and inhalers aren't in the same bag and they should be....I need them both.

525: I don't like having my inhaler because it's different and I get problems with it.

310: Good is when I don't cough and when I have my friends and they are there not staring at me. I'm writing this [on their picture].

Following upon from this other practical strategies that children stated they had to help manage their asthma included finding fresh air:

³⁰ Children aged 8-9 school 3

³¹ Children aged 7-10 school 6

³²444: you see I need space and air it is good air that I need.

777: I need to be outside and get the space it helps me lots you know...

Wrapping up warm, avoiding things they knew made their asthma bad, and trying to get their friends to accept them appeared to be the most common strategies.

Figure 17 is a picture drawn by a child which illustrates the majority of these points.

³² Children aged 10 school 5

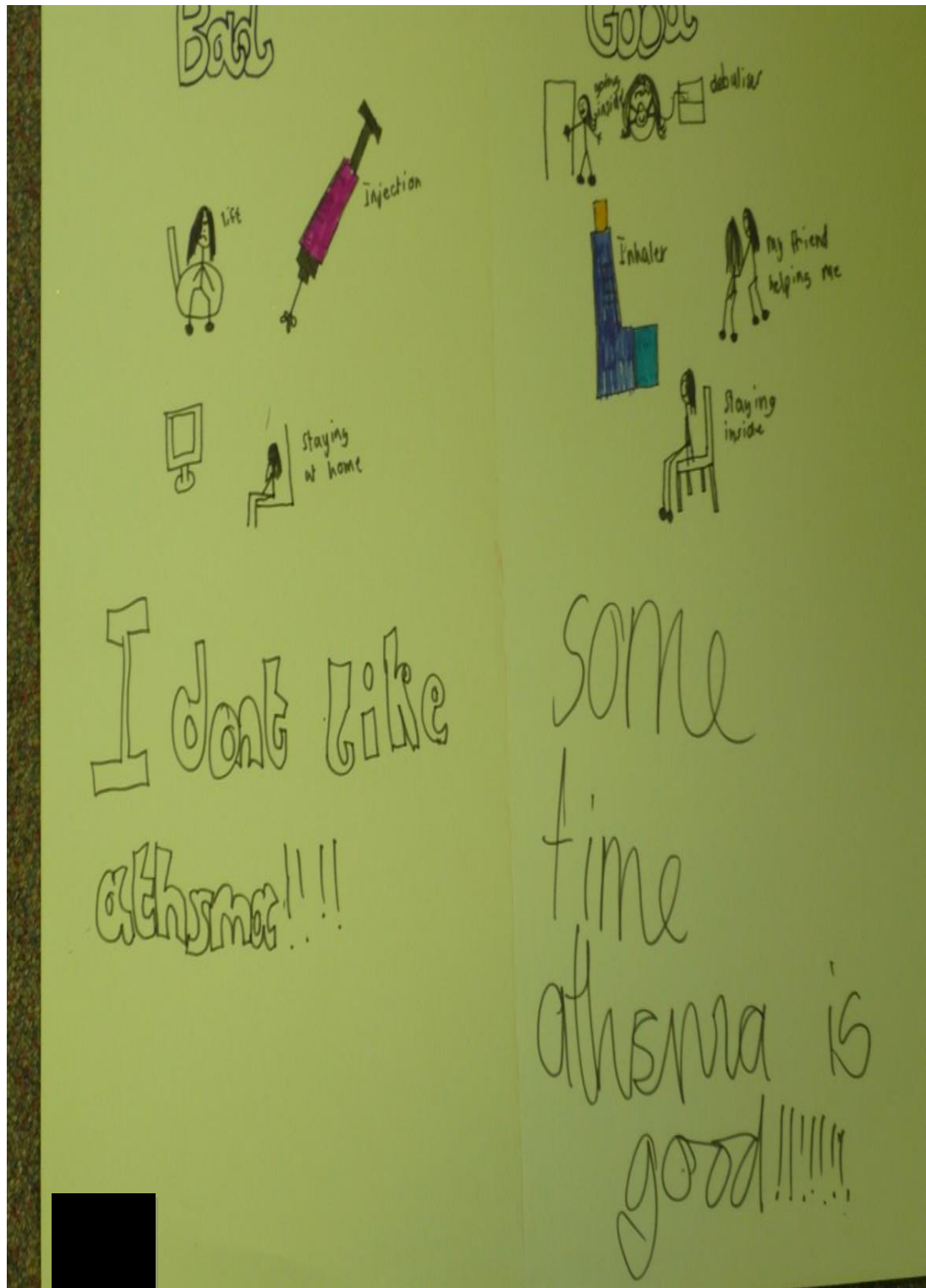


Figure 17: a child's drawing of things that help to manage asthma in school.

6:3.2v Asking the school staff- those that are helpful and those that are not.

Children in this research discussed school staff and their importance to helping them manage asthma in both positive and negative terms.

Positively they reported that some school staff were helpful.

³³1000: Mrs B----- she is nice and good you know she goes and gets us some water and I always look for her to help me.....yeh I like her and she is nice but the rest I don't think they're good enough you know, they don't know it all and I don't bother with them.....

CF: what do you mean good enough?

1000 well...you know they they shout and say ITS JUST ONE OF THOSE THINGS AND SIT DOWN IT'LL GO and I I don't like it shouting it happens all the time so I, I just tell Mrs B.....

In another interview similar things were said.

³⁴11a You see, when I need to know how bad it is I get on with it and then I just sort of look up, and look out for Mr C and he gets me better, I like him he is nice and gets on with me and that's good.

18 Yeh that's it you see Mr C is good and I like him as well he is nice and that's it that's good and I like it.....

28. Yeh that's right I like him and he helps me.

CF. So what is about him that is different?

11a Well you see... he talks quiet and doesn't shout ... that's important and he he you know.. he believes us and that is good that he believes us and we can get him to help.

³³ Child aged 8 school 2

³⁴ Children aged 7-9 school 3

Other children talked positively concerning school meal assistants that they particularly found helpful.

³⁵88: Mrs B and Mrs F they are good, they understand and tell us to sit down and get our breath back. That's good and I like it because that's good.

10. Yeh that's right they're good and I think that helps letting us to think about things that are helpful and letting us sit down and get our breath back that's good. They don't shout and tell us off they believe us and that is important.

Another child stated concerning school meal assistants the following

³⁶168: All they say if I say that my asthma is bad just to go away and take your inhaler and they don't know how it feels..

It appeared that having staff that were helpful, who believed them and did not shout and understood what it was like to have asthma was good.

Conversely asking children what is not helpful resulted in the following type of response.

³⁷987: Mr S he shouts all the time and says WHY DO YOU NEED YOUR INHALER...you're alright it will go and then sit down and get on with it...

77: Yeh Mr S I never tell him, he doesn't let me know what is happening and he is horrid and says that things are not as though I need my inhaler so don't worry about it....

442: yeh yeh, that's it that's how he is and so is Mrs F and Miss B they say the same and don't believe us and always shout and thing that is bad and makes me feel bad because I need to do things and that helps me ...my inhaler helps me and that's it.

One child produced a list of things that were good and helped her with her asthma and things that were bad and did not help.

³⁵ Children aged 7-8 school 7

³⁶ Child aged 8 school 4

³⁷ Children aged 7-9 school 5

³⁸700a So you see these are the things that help me and these are the things that don't.....yeh that's it these don'tbut you see really the good things never really happen and they have never been in this school.. all the bad things happen and none of the good....

(see Figure 18 below)

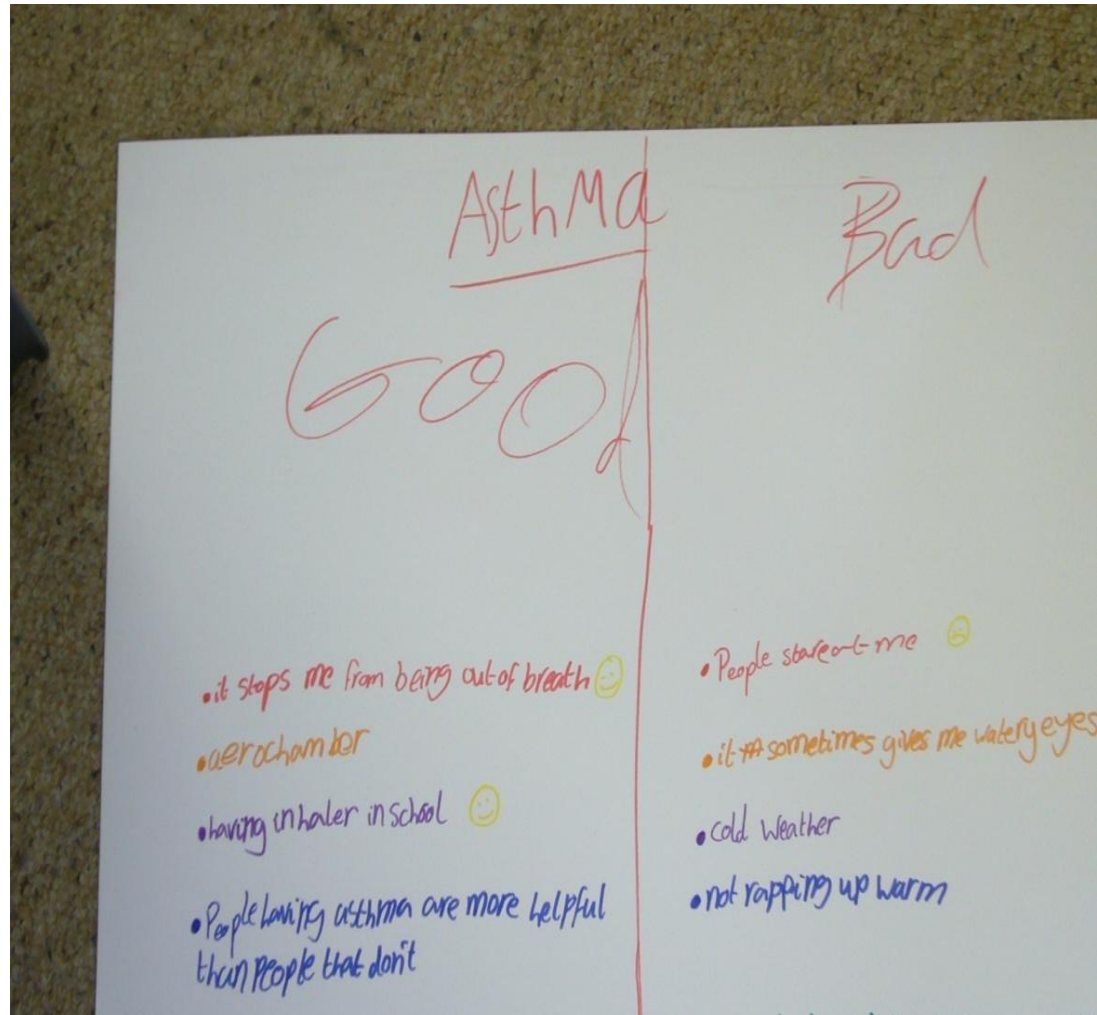


Figure 18: A list of good and bad things that help with asthma.

³⁸ Child aged 7 school 4

6:3.3 How it feels to have asthma in school.

Children in this research generally stated that having and managing asthma in school was a 'trouble and nuisance to them' and not a 'nice or good' experience, they discussed how it impacted upon their participation in daily school life. Often stronger words than nuisance was used and they either reflect the strength of feeling that each child had about their asthma impacting upon their school life, or are used in every day speech by the children and are thus accepted as part of their vocabulary.

³⁹618: Its horrible.

CF: Is it horrible 618 why is it horrible?

618; 345; 478; 321: yeh...yeh (consensus from the rest of the children).

618: Well you cough all the time and it is really annoying if you are playing games and it gets really distracting and you get out of breath.....

618: It's horrible, bad and yucky.....

Other children used words and phrases along similar lines to describe what it was like to have asthma in school. However, their consideration about what it was like to have asthma depended upon their exposure to asthma in other contexts. For example family members with asthma can have quite a significant influence upon how children perceived asthma and its effects upon their school life.

⁴⁰765: its *****[expletive removed] bad, every time I try and get help in this place [school] with my asthma it doesn't happen. They don't care....I can't do my ***** [expletive removed] rugby and football and it is bad, really really bad.....me Dad says he is ***** [expletive removed] by his asthma and I agree it is.

³⁹ These four children are aged 6-8 years in school 3

⁴⁰ 765 and 867 are children aged 10 -11 in school 1.

867: I can't believe how much it bothers me....it gets really on my tits, each time I gets it bad I'am mind, I'am off to try and get it sorted but I have to give myself more time mind, to get across the playground.....I can't do it in the time and I gets upset its bloody awful having it.....

765: yeah...yeah that's how it is its like that you can't get on with anything it stops it all....I can't manage it like you know its hard its hard work to think about this and do me school work so I don't bother you know... don't bother...

CF: don't bother?

765: well if I can't do it and I just die then that's it isn't it, I just do it and then it don't matter... asthma is bad you know it kills me uncle so I know its bad so I don't bother now.....

..... [quite a long pause]I don't bother with me work or me asthma I lets it get on and I think I'll do me football when I'am better .

Such strong words and impact upon daily life not just school was held by others in this research.

⁴¹**121: I have asthma see.... It is just like that and I get on with it....I make sure that the thing, the thing is I need to get it sorted and manged 'cos its really really bad, I find it really really really bad and I need to, need to have it better so I can do school stuff.....school work and play I like to play but its too bad.**

100: yep, its bad but we all here have it so you see we all think its bad and that's why we wont to do it... bad to stop all the others.

It appeared that the word quite frequently associated with asthma is 'bad'. Reading through the transcripts this is a word that occurs almost on every page when the children described what it was like to have asthma in school. Children drew pictures that tried and represented how they felt about having asthma, see Figures 19 and 20.

⁴¹ Children aged 8-9 in school 2

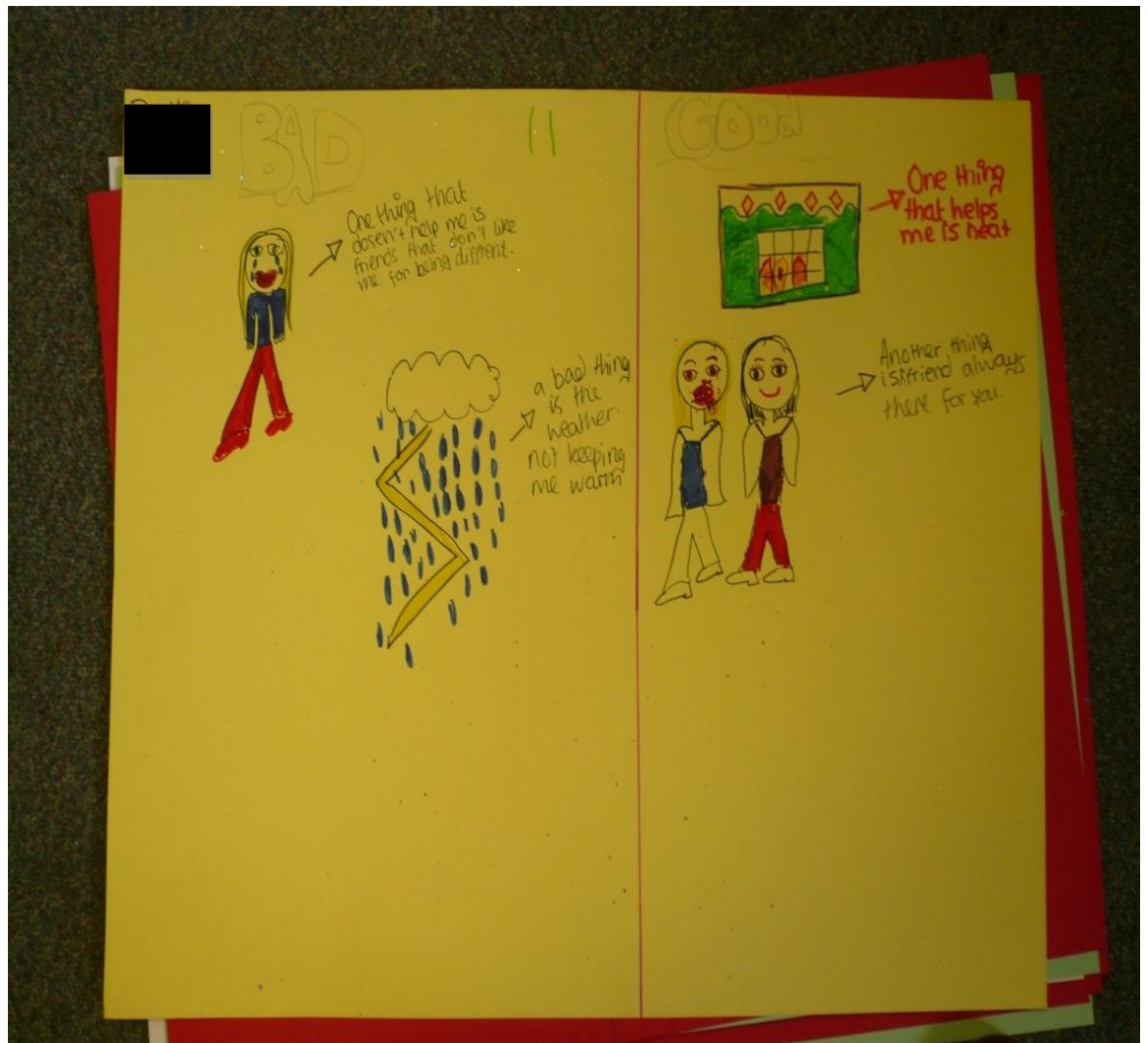


Figure 19: Drawing by child illustrating the good and bad things about having asthma.

The following picture (Figure 20) includes the word 'sloth' which the child concerned stated summarized how she felt when compared to her friends and not able to participate in all activities.



Figure 20: Drawing by child illustrating how she feels about having asthma in comparison with her friends who do not have asthma.

Bad things that children felt about their asthma, or that made their asthma worse can be seen exemplified in the picture below (Figure 21), drawn by a ten year old.

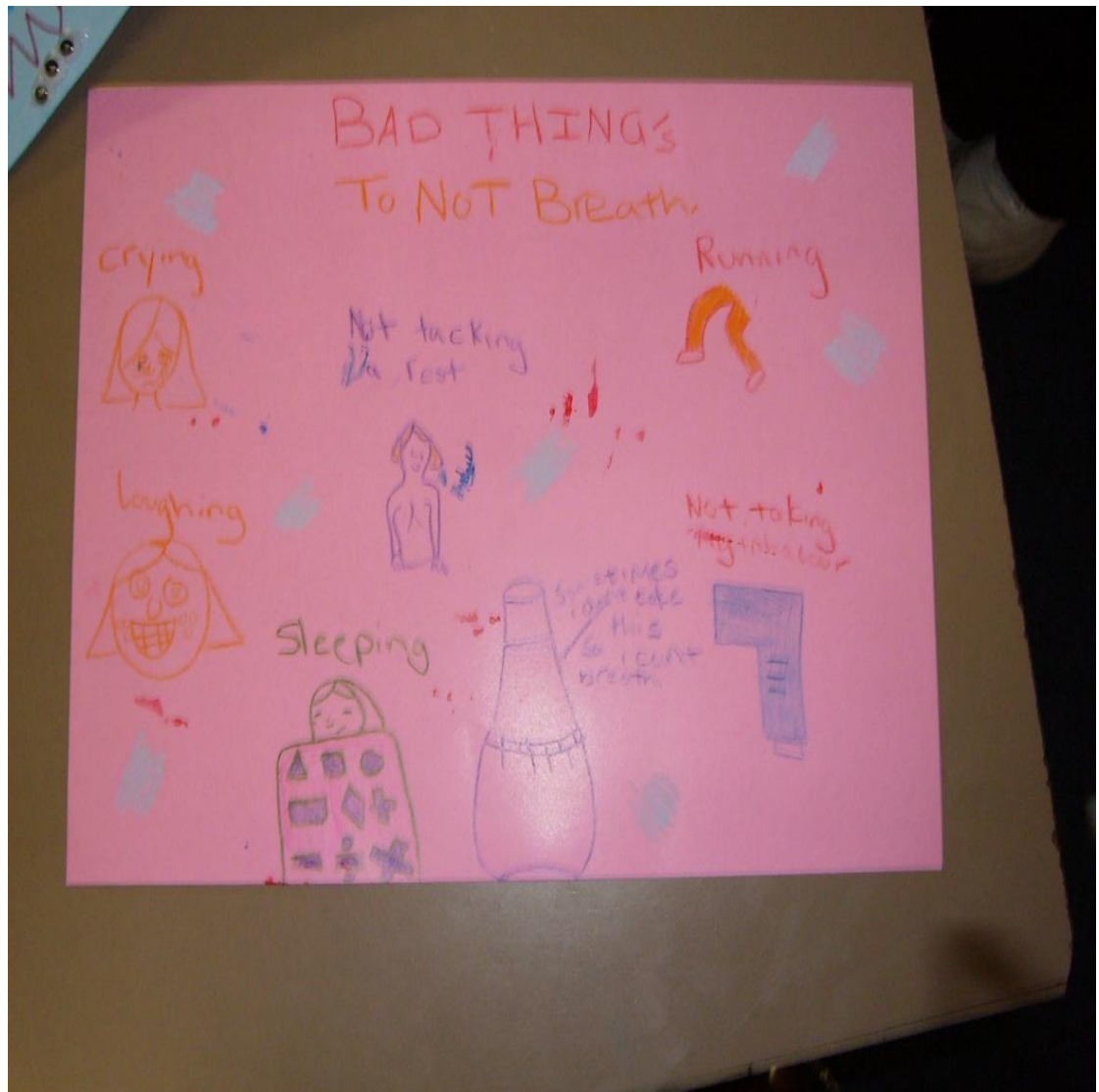


Figure 21: Bad things associated with asthma.

Children with asthma felt different and often lonely, with a reduced friendship group. They felt that they were stared at because they were different, and that being stared at was upsetting. This effect of being stared at and feeling isolated is shown well in the pictures. The children who drew these pictures all used similar words and phrases to those discussed and added to their impact by considering drawing them in

their art work. They then referred to this clearly in their explanation of their pictures.

Feeling isolated or different from their peers, missing out is an important effect of having asthma that many children comment upon.

⁴²**423: I feel really annoyed and stuff and frustrated since it stops me doing what I want to do when I'm in the school.**

767: No never.....I am never stopped from doing anything cause when they are doing their runs and stuff I sit on the carpet and I do my inhaler but when they come and sit down on the carpet they all come and look at me and I say 'go away and go away' but they always come back and I have to take it then I have to take my inhaler in that case and I can see that its bad.

Other children stated quite forcefully what happened when those people without asthma found out that they had asthma.

⁴³**600: You know I had lots of friends, we all got on and that was good and we knew each other really well. I had X--- and Y--- and that group and we all liked each other we had similar things and then... then I got bad and needed to use my inhalers. They all just stood and watched, then they laughed and went off and now I don't have themthat's how it is I don't have them anymore and I want to be their friends.**

Figure 22 is drawn by child who stated that he felt all his friends screamed at him so it wasn't worth having any friends in school.

⁴² Children aged 9 school 4

⁴³ Child aged 11 school 6



This is a picture of children screaming when they realized that the child drawing the picture had asthma, the box with the numbers upon it is the child's nebulizer held at school.

Figure 22: a drawing of a child showing how he feels others think about his asthma.

Children in this research seemed to agree that having asthma was not a positive experience; they concluded that it has more negatives than

positives associated with it and in the words of the final picture in this section presented below it is 'horrible'.

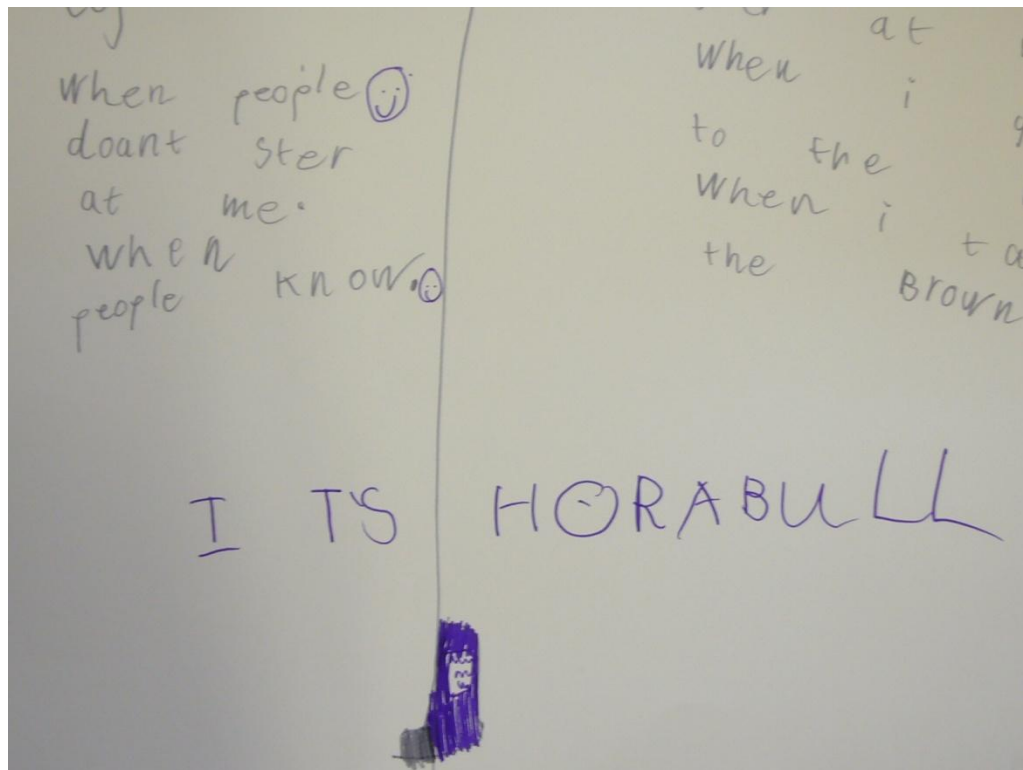


Figure 23: Seven year old child's drawing - what she thinks about asthma.

This section of the research findings has explored what children felt it was like to have asthma, what asthma is and how children managed their asthma in school. Please refer to the chapter eight and nine for consideration of how this fits together regarding the quantitative data collection and the experiences of the school staff.

7: Children's perceptions of their asthma associated quality of life (QoL).

7:1 Chapter outline.

This chapter will present an overview of the concept of 'Quality of Life' (QoL) linking it to the research questions and current clinical and academic literature. It then develops into a consideration of the choice of QoL questionnaire, how QoL was ascertained in this research (method) and then a detailed presentation and discussion of the results.

Discussion focuses upon how the results relate to and address the relevant research questions. Where appropriate some cross reference is made to qualitative components of this research. The conclusion of this chapter summarizes the methodological issues that affect the analysis and thus the overall statements that can be made in the consideration of this data.

7:2 What is understood by 'quality of life'?

Bowling (2005, p. 7) states that

In general terms quality can be defined as a grade of 'goodness'. Quality of life, then is about the goodness of life,

and in relation to health is about the goodness of those aspects of life affected by health.

However, health related quality of life is but one dimension of the wider definitions associated with 'quality of life'. There are many wide reaching, multi layered and amorphous concepts in relation to quality of life, with a wide range of definitions, with inconsistent structures (Farquhar 1995) from diverse theoretical backgrounds (Patrick and Erickson 1993).

Considering the question "what is quality of life?" generates distinctly variable answers depending upon whether it is being asked at a macro level (considering the context of society which is objective in focus) to micro level (considering the individual which is subjectively focused). The former includes reference to income, employment, housing, education, living and environmental circumstances. The latter includes perceptions of overall quality of life in the context of individual's experiences and values. Quality of life appears to be a complex collection of interacting objective and subjective dimensions with most researchers focussing upon its multi –dimensionality (Lawton 1991, Bowling 2009).

Thus the term 'Quality of life' (QoL) is defined in a multitude of ways, which can make its measurement and incorporation into scientific study difficult (Fallowfield 2009). Beckie and Hayduk (1997) have presented the argument that multi-dimensional definitions of QoL cause confusion between the dimensionality of the concept with the multiplicity of the causal sources of that concept. This further expounds the argument that QoL should be considered as a one-dimensional concept with multiple causes, and thus only possess a one-dimensional QoL rating.

Illness and treatment affect the physiological, social and economic well being, as well as the biological integrity of individuals. Thus any definition of QoL must be all encompassing yet still allowing individual components to be delineated. This allows the impact of

different disease states or interventions on overall or specific aspects of QoL to be determined Fallowfield. (2009) cites the following characteristics (see Table 4) as core components of multidimensional Health Related QoL (HRQoL).

Core components of multidimensional HRQoL assessment
Physical
Functional
Psychological/ emotional
Social/ occupational

Table 4: Core components of a multidimensional HRQoL, adapted from (Fallowfield 2009)

In some occasions studies employ a questionnaire that measures only one construct, *inter alia* it is one-dimensional, such as pain (brief pain inventory (BPI) Cleeland 1989), or an anxiety inventory for example the Spielberger state/trait anxiety inventory (1983).

Fallowfield (2009), Phillips (2009) and Bradley (2001) state that it is preferable that each of the scales within a multidimensional questionnaire is shown to have one-dimensional characteristics, thus ensuring that each themed component of a multidimensional questionnaire assessing QoL can be analysed or used as a standalone assessment of that measure, or combined together to provide the overview of the assessed influence of all the strands upon total QoL. It seems reasonable that QoL is influenced by many causal variables, which can be assessed as independent factors such as the influence of pain upon QoL as determined by the Brief Pain Inventory cited above, or as a consequence of the interplay of many factors influencing quality of life and assessed using QoL tool reviewing many factors for example the affect of asthma upon QoL.

7:3 Primary reasons for measuring the effect of asthma upon QoL

The primary purpose of any asthma treatment is to improve the quality of patient's lives (BTS/SIGN 2009, GOLD 2007), since in the case of asthma it cannot be cured. Guidelines on asthma management within the United Kingdom (UK) state that the aim of asthma management is control of the disease (BTS/SIGN 2009).

This is defined as:

- No night time symptoms;
- No night time awaking due to asthma;
- No need for rescue medication;
- No exacerbations;
- No limitations on activities including exercise;
- Normal lung function.

(BTS/SIGN 2009 page 33 asthma guidelines)

However, in clinical practice patients may have different goals and wish to balance the aims of asthma management against the potential side effects and/or inconvenience of taking medication necessary to achieve perfect asthma control (BTS/SIGN 2009).

Thus it is expected that every clinician therefore, will make implicit subjective judgements about QoL when treating a patient.

Very few clinicians make explicit, objective assessments about QoL using validated tools and instruments (Fallowfield 2009). However, formal assessment of QoL is now a mandatory requirement in clinical trials, but outside this setting most clinicians depend upon informal appraisal believing clinical judgement to be superior to formal assessment (Fallowfield 2009). Earlier work by Clarke and Eiser (2004) found in their systematic review of the use of QoL measures in clinical practice that they were rarely used, despite the emphasis in

practice to use patient centred outcomes within both chronic disease and paediatric management.

Thus considering the aims of asthma management and treatment, it is expected that asthma should not affect individuals' quality of life. However, the observed phenomenon worldwide is that asthma is affecting quality of life and that in some circumstances this is quite significant (see chapter 2), causing across the world significant impairment in daily functioning of individuals with asthma (Warman *et al.* 2009, Kurukulaaratchy 2008).

7:3.1 The link between QoL to the research questions.

The overall research aim is to explore children's experiences of asthma in primary schools. It is thus necessary to consider if asthma is perceived to be influencing quality of life in children with asthma (the research participants). If asthma is perceived to be influencing their asthma associated quality of life, how the children (research participants) manage this in the context of school and what components of asthma associated quality of life they perceive as important in school require exploration and consideration.

It is expected that the burden of asthma/ or impact of asthma upon quality of life will be significant. Since research to date (Jackson *et al.* 2006, Warschburger *et al.* 2004, Roder *et al.* 2003) indicates that despite the utilization and recommendations of asthma management guidelines, for many reasons asthma is still not managed sufficiently to eliminate its effect upon quality of life.

7:3.2 Consideration and choice of disease specific QoL tool.

Asthma is a disease that affects a myriad of components within daily life (please refer to the aims of asthma management section 7:3).

This multiplicity associated with asthma and its effects upon components of daily life (experiences) requires specific consideration of its effects upon QoL, and thus in order to qualify this affect a multidimensional asthma specific QoL tool must be utilized. Utilizing Health Related Quality of Life (HRQL) tools that are not specific for asthma can cause significant omissions in data collection and limit statistical inference from the data set (Montalto *et al.* 2004). In order to understand more fully the experience of having asthma in school for young children particular focus must be paid upon how children are managing their asthma, what particular components of their life asthma affects and how they perceive this. This is exactly the key components of disease specific QoL tools and thus their use in exploring this aspect of children's experiences of asthma is essential.

Disease specific QoL measures will review all components of daily life as indicated in previous chapters, and do not just identify the child's time in school. However, school although a brief period of a child's day (Tinkelman & Schwartz 2004) has an important and powerful impact upon childhood development and well being (Gentile 2008). Both the commonly used disease specific QoL measures for childhood asthma have a high focus upon activities undertaken in school (Juniper *et al.* 1996, French *et al.* 1994). Furthermore, in consideration of the research context and questions the first research question is: What are children's experiences of asthma within primary schooling? One approach to this is to consider what do children with asthma perceive as the effect of having asthma regarding the level of symptoms, reduction in activities and emotional sequelae? This affect will be expressed in school in interactions with peers, participating in school sports, coping with daily school related activities and their QoL will provide an indication of how children manage and experience asthma in school.

7.3.3 Can children complete QoL questionnaires reliably?

Children with asthma are fully able to consider the impact of asthma upon their well being (Guyatt *et al.* 1997, Sawyer *et al.* 2001) and responses are more likely to be representative of their reality if undertaken away from parents and carers (Tai *et al.* 2009, Juniper *et al.* 1996a, 1996b, 2008). In fact separate questionnaires have been developed to assess parents/ carers perceptions of the impact of asthma upon children's quality of life (Juniper 1996c), since parents/ carers frequently underestimate the impact upon physical well being and emotional influences compared to children's individual responses (Juniper 1996a, 2008). Furthermore, these researchers present their perceived uncontroversial evidence for children with asthma completing questionnaires without parents/ carers present in order to ascertain a measure of children's true asthma related quality of life. Yoos *et al.* (2003) confirm Juniper's earlier work that children are fully able to accurately detect their symptoms of asthma and how they impact upon their ability to function in everyday life from in their research five years of age and in some cases younger.

7:3.4 Discussion of the choice of disease specific quality of life tool – Paediatric Asthma Quality of Life (PAQLQ).

The choice of instrument depends almost entirely upon the reason for measurement and the primary concepts of interest (Fallowfield 2009). The choice of QoL tool, Hyland (2003) states can be undertaken by anyone who has both a good understanding of the disease and an understanding of the research requirements. Hyland then continues *ibid.* that a QoL tool should have adequate psychometric properties but beyond that this rarely plays a part in the decision making. Psychometric properties are important to consider

and should be able to demonstrate in the choice of QoL tool, since it is known that particular personality traits influence perceptions for example neuroticism, negativity and depression all influence perception of factors measured in QoL (Guyatt *et al.* 1992, Hyland 2002). However, although individual perceptions are an important factor in considering QoL, many researchers believe that in the context of health there is empirical evidence that most people hold a set of common values in relation to what gives quality to life. Similarly this can also be applied to what makes up the important things in life, although this may vary by people's socio-demographic characteristic (Bowling 2005, WHO 1995).

Hyland (2002) states that all QoL measures should be able to demonstrate that they correlate well with other QoL tools for example the SF-36. The SF-36 is arguably the most important and frequently used generic Health Related Quality of Life (HRQoL) assessment tool (Bowling 2005), this is a multipurpose short form health survey comprising of 36 questions which provide an eight scale profile of functional health and well being scores (Fallowfield 2009).

Fallowfield (2009) further suggests that the key issues when choosing a QoL tool are to review the instrument for coverage of items of interest and to ensure that it is valid and reliable. She urges caution to be applied when citing the choice of using a QoL tool as (I paraphrase) because it is used frequently in the research literature.

Disease specific measures are considered to be of primary importance in QoL tools which are focussing upon the impact of chronic illness in children, where daily self management of the disease has an impact upon their physical and psychological well being (Clarke and Eiser 2004).

Children with asthma are troubled not only by symptoms such as shortness of breath, cough and wheeze, they are also bothered by the physical, social, educational and emotional impairments that they

experience as a result of having asthma (Usherwood *et al.* 1990, Townsend *et al.* 1991, Nocon 1991, Christie *et al.* 1993, Gentile 2008). Furthermore, the impact of asthma upon days absent from school, engagement and attention within school and its effects as an ever present stressor are assumed to influence children such that they will have low school performance (Celano & Geller 1993), have behaviour problems and feel socially isolated (Bender 1995, Eiser 1990). However, this is summarized responses from a wide range of research conducted across various populations utilizing varying and in some cases questionable methodology.

Measurement and assessment of the perceived effects of asthma upon QoL experienced by children within school will thus explore within this research setting some of the above factors. It is worth noting that research evidence to date exploring correlations between quality of life and asthma is somewhat limited, carried out decades ago in the majority of cases and not within the UK.

Juniper *et al.* (1996) developed an instrument to measure QoL in children with asthma; this is the Paediatric Asthma Quality of Life Questionnaire (PAQLQ). The PAQLQ is claimed by the authors as being rigorous in its design (Juniper *et al.* 1996a), and Bowling (2005) states that it is an example of a disease specific quality of life tool. The PAQLQ(S) is frequently used in the research involving children with asthma as a quality of life measure (Gentile 2008, Gent *et al.* 2008, Sawyer 2001). The PAQLQ is widely used as a research tool to assess the efficacy of new therapeutic medication for those with asthma, as well as a tool to assess the impact of a specific intervention in asthma management (Jackson *et al.* 2006, Kuruklaatchy *et al.* 2008). However, as yet it is not widely used in clinical practice as an indicator of children's quality of life with asthma and as an assessment of functional well being alongside consideration of the efficacy of current therapeutic intervention (Burkhart 2007, Kuruklaatchy *et al.* 2008).

7:3.5 Choice of which specific Paediatric Asthma Quality of Life Questionnaire (PAQLQ) devised by Juniper et al. to use.

The PAQLQ contains 23 items that children with asthma have identified as troublesome in their daily lives. It is validated for children aged between seven and 17 years (Juniper 1996a), and its development utilized well established methods for quality of life questionnaire development, the importance model (Juniper *et al.* 1996b). The PAQLQ is a fairly simple questionnaire; its original structure is to be administered by an interviewer reading questions and the children (participants) writing their answers upon a pre printed answer sheet. Several versions of the PAQLQ now exist, which allow children to read and answer the questions independently of an interviewer (mini PAQLQ) or consider the impact of asthma upon three specific standardised pre selected activities PAQLQ(S) with the S indicating that it is the standardised version.

The PAQLQ(S) was selected to be used in this research. This choice was made upon two factors: the fact that the PAQLQ (S) is now more commonly used than the original PAQLQ in large research trials; and also since these interviews were not intended to be repeated there was no need to identify individual activities with the children to allow monitoring of their asthma over time which is an advantage of the PAQLQ. The mini PAQLQ did not provide the breadth of data that could be acquired using the PAQLQ(S) and also required children in general to be above the age of 10 (which would exclude the majority of these research participants). Consequently, to generate the maximum data for analysis and greatest data quality for consideration against other research the interviewer based PAQLQ(S) was chosen. There is strong evidence for the validity of PAQLQ(S), it has internal and external validity (Bowling 2009), it is routinely used in clinical research trials and that it correlates and

identifies well to the standard QoL indices and asthma indicators of respiratory function such as peak flow measurement (American Thoracic Society 2012, British Thoracic Society 2010, Israel *et al.* 2008) and personal experience of using this in previous research (Francis 2001, Salisbury *et al.* 2002) provided the rationale in the use of this quality of life tool in this research.

As discussed in the initial paragraph of this chapter the following section now considers both the exact structure of the PAQLQ(S) tool and also the method employed to gain the data discussed later.

7:3.6 Structure of the PAQLQ(S).

The PAQLQ(S) interviewer administered questionnaire is reproduced in Appendix (vii), including the pre-printed response sheet and the cards referred to as 'green' and 'blue' which the children refer to when selecting their response to each question.

Juniper *et al.* (2006) state that the PAQLQ(S) should be the first questionnaire completed during a clinical situation, since any prior discussion with a health care professional may influence how they answer the questionnaire. The questionnaire should be administered in a relaxed atmosphere with no parents/ carers present, that clarification regarding the timescale should be obtained from the respondents ensuring that their perception is correct and that they understand the seven point scale fully. Children aged seven or above should be able to complete the questionnaire. Problems with literacy and numeracy have apparently been considered but no mention is made as to how they have been considered and the following quote does not add insight into this

“therefore, problems of understanding should be minimal”

(Juniper 2004, page 14)

Thus in summary concerning the administration of the PAQLQ(S) Juniper *et al.* (2006) state that in using the interviewer administered questionnaire the following conditions and considerations should apply:

- great care should be taken to ensure that the environment is supportive, that children answer the questions without parents/ carers intervening;
- that the interviewer should read the questions as written without interpretation and allow the children to select their responses independently of the interviewer;
- that the interviewer should stress there are no right or wrong answers;
- that at the end point of the questionnaire the interviewer should check to ensure that no data is missing and direct the children to return to any response not completed and attempt to provide their answers.

The PAQLQ(S) has 23 questions (please see appendix vii); each question has a choice of seven responses which are expressed both numerically and as written phrase with a recall period of one week. There are three domains: symptoms, activity limitations and emotional function, all of the activity questions are generic which means that each child identifies and scores these pre set activities in which they are limited by their asthma. Table 5 indicates how the PAQLQ(S) score should be calculated.

Domain	Question numbers.	Calculation of score	Possible score range
Overall PAQLQ(S) score (HRQoL)	1- 23 inc.	Arithmetic mean of all numeric responses, (add all 23 responses together and divide by 23)	Between 1-7
Activity limitations	1,2,3,19,22	Add together numeric responses to these questions and divide by 5.	Between 1-7
Symptoms	4,6,8,10,12,14,16,18, 20,23	Add together all numeric responses together and divide by 10	Between 1-7
Emotional function	5,7,9,11,13,15,17,21	Add together all numeric responses and divide by 8.	Between 1-7

Table 5: How to calculate the PAQLQ (S).

7:3.7 Interpretation of the PAQLQ(S) - Interpretation of 7 point scale.

All the questions in PAQLQ(S) ask about problems that occur as a result of asthma. Thus the questionnaire cannot be completed by anyone who doesn't have asthma and thus there are no 'normal values'. The best score is 7.0 which would mean that the child perceives they have no HRQoL impairments due to their asthma. However, when the score begins to fall below 7.0 the child is experiencing some degree of asthma associated quality of life impairment. Juniper (1999) suggests that if you wish to label the degree of impairment with a verbal label, the best way is to look at the responses upon the seven point scale (of either the blue or green card) and selecting the nearest numerical score to the value obtained use the verbal descriptors associated with that score, and then use this information to gauge the degree of impairment. Thus 1.0 indicates severe impairment and 4.0 indicates moderate impairment.

7:3.7i Minimal important difference (MID).

It is difficult to intuitively understand (Juniper *et al.* 2006) and then interpret the results from the PAQLQ(S) against direct respiratory lung function values. Familiarity with the questionnaire allows rapid assessment of asthma associated quality of life akin to health professionals who can easily assess the effects reduced respiratory lung function values would have upon exercise tolerance. Thus to add in the interpretation of PAQLQ(S) scores Juniper *et al.* (2008, page 82) have devised the minimal important difference, which is

“the smallest difference or change in score which patients perceive as beneficial and would mandate, in the absence of troublesome side effects and excessive cost, a change in the patients management.”

They have established that the MID for the PAQLQ(s) is close to 0.5 on the 7 point scale. This and their text supporting the use of MID

indicate that the scale from 1-7 is in their opinion both an interval and a nominal scale, and should be considered as such in any interpretation of the data obtained. They consider that some caution needs to be applied in the interpretation of this 0.5 as the MID into clinical practice since it would appear that there is some scatter about this value and that children vary in what they consider to be an important quality of life change. However, consistent agreement is generated around the data gathering and associated values and the effect that lower quality of life scores have upon children's functioning and well being and these should be the focus for analysis.

The PAQLQ(S) results are thus considered generally by mean values only. In other questionnaires it is possible to produce data considering the distribution around the mean (confidence intervals, standard deviations). Juniper *et al.* (2008) do not fully support this level of analysis with their PAQLQ(S), producing alternative forms of consideration in relation to numbers needed to treat in order to detect a response to an intervention.

The following section discusses how in this research the PAQLQ(S) was actually used (method of administration) and the data obtained, this is in essence the method followed in order to obtain QoL data from primary school children in this research (respondents).

7:4 Method used to gain QoL data from research participants.

Permission to use the PAQLQ(S) was obtained from the authors. Identification of all research respondents occurred as follows (please refer back to 3:8.6 to 3:8.8 for more detail). All schools that agreed to participate in this research with children aged seven and over (thus excluding infant schools) identified children with asthma who then were given by the schools the information sheets and consent forms (appendix iv). There were seven schools that met this

requirement. Those children from each school who agreed to participate in this research and met the inclusion criteria were asked to undertake two research related tasks, the first was the qualitative interviews in which children were asked to draw and talk about their asthma and the second was the completion of the PAQLQ(S).

Immediately prior to completing the PAQLQ(S) the purpose of the questionnaire was fully explained to each respondent and any questions answered. All children were reminded that they did not have to complete the PAQLQ(S) and they could leave at any time.

This was administered following the suggested protocol as outlined by Juniper et al. (2004). Appendix viii outlines in detail the method used in this research to collect QoL data and any additional considerations that were undertaken to maximise responses to the QoL questionnaire in the school environment.

7:4.1 Data storage and method of analysis.

Unique identifiers for each child have been used and these are identical to those the child was given in the interview stage and picture drawing of this research. Thus it is possible to compare interviews, pictures and quality of life data for each individual research participant.

The original response sheets for each child are kept securely for cross reference. These original sheets are not manipulated or annotated in any respect. The data contained upon them is transferred from paper records to electronic records as below. All responses to the PAQLQ(S) were double entered into appropriate designed excel spread sheets. Comparison between each spread sheet was made to identify any data entry errors. These were then solved by reference to the original participant's response sheet. This produced one comprehensive and large set of electronic data for

analysis, and a second original copy was kept for cross reference should any corruption occur to the data or clarification be required.

Analysis of each individual respondent's PAQLQ(S) then occurred as follows:

- Each respondent's overall PAQLQ(S) score was calculated;
- Then the score for each participant's sub-domains within the PAQLQ(S) were calculated these are activity, symptoms and emotional functioning.

7:5 Results.

7:5.1 Original PAQLQ(S) Data.

Tables containing the calculated PAQLQ(S) score for each research participant, and their individual results for the three domains, activity, symptoms and emotional function are placed in appendix (ix). These are included to allow consideration of the completeness of data and analysis should this be required. The discussion and consideration of the results that follows in this chapter has full reference to appropriate summaries of this data which are represented as required in both table and graphical forms. Table 7 contains summary descriptive data for the gender composition, number in each school year and overall school participation numbers for the children who were research participants in this phase of the research.

In this thesis seven schools are considered throughout. As discussed in chapter four this is because these are the schools for which complete research data was obtained. Refer back to Figures 6 and 8 which indicate that 15 schools were selected to participate in this research, this was more than the initial schema submitted to gain

faculty research ethics approval as outlined (Figure 5) and was as discussed in the methodology to allow for natural attrition from the research participants. In fact the figure of seven schools for which complete research data was obtained is as a consequence of the QoL tool that was selected not being deemed suitable for completion by children under the age of seven years and thus no QoL data was obtained for children in infant schools.

Table 6: Summary descriptive data for the child research respondents, broken down by each school.

Total Number of research participants N= 138	Number in school one	Number in school two	Number in school three	Number in school four	Number in school five	Number in school six	Number in school seven.	Girls.	Boys.	Total number in each school year
School year three	3 girls 3 boys	2 girls 3 boys	4 girls 3 boys	5 girls 2 boys	3 girls 4 boys	3 girls 4 boys	2 girls 4 boys	22	23	45
School year four	1 girl 2 boys	2 girls 2 boys	2 girls 3 boys	3 girls 2 boys	2 girls 2 boys	5 girls 1boy	2 girls 3 boys	17	15	32
School year five	3 girls 2 boys	2 girls 3 boys	2 girls 1boy	1 girl 3 boys	2 girls 2 boys	1 girl 2 boys	3 girls 1 boy	14	14	28
School year six	2 girls 1 boy	1 girl 4 boys	2 girls 4 boys	1 girl 2 boys	2 girls 5 boys	3 girls	2 girls 4 boys	13	20	33
School total	17	19	21	19	21	19	22	62	76	138

School Number	Ethnic composition of school pupil participation in QoL data collection. Ethnic codes used as those used in 2001 census please see next column.	Guide to ethnic codes used in this thesis (as those used in 2001 UK census).
1	WHB = 5; MWB = 4; MWA = 4; BLF = 3; CHE =1	WHB = White British
2	WHB = 11; MBA = 3; MWB = 2; BLF =1; BLB = 2	MWB = Mixed white and black Caribbean
3	WHB = 14; MBA = 5; BLB = 2	MWA = Mixed white and Asian
4	WHB = 11; MWB = 5; AIN = 2; MWA = 1	AIN = Indian
5	WHB = 12; MWB = 6; MWA = 1; BLF =2	BLB= Black or Black British Caribbean
6	WHB = 8; MWA = 4; AIN = 1; BLB = 3; BLF = 2; CHE =1	BLF = Black or Black British African
7	WHB = 16; MWA = 4; BLB = 2	CHE = Chinese ethnic group

Table 7: Ethnic composition of the research participant children in each school.

7:5.2 Discussion of Tables 7 and 8 – overall summary data of research participants in each school.

Consideration of this data reveals that the seven schools had in total between 17 and 22 children participating in the QoL data collection phase of this research. Across all four school teaching years, school year three had the greatest number of participants at 46 and school year five had the lowest number of participants at 28. This was the majority of research participants that completed the qualitative phase of this research (as discussed in section 6:3.4 children with specific learning and conceptual needs were excluded from this quantitative phase, in total this was 11 children).

Nevertheless, despite the low numbers included within each school assuming that the incidence of asthma within the school aged range studied represents the then UK average of 10- 15%, within each school it is likely that nearly all the children with asthma participated in this research stage. This was further confirmed by reviewing the number of child related consent forms returned to the school declining to participate in this research.

Thus although there is relatively small numbers within each school and within each school year that participated in the QoL data collection, this might be the majority of asthmatic children in all seven schools. The application of statistical analysis is thus limited as defined by numbers included within the research data set and rests mainly upon the use of descriptive statistics to provide detail concerning the population characteristics and variations within the population. However, where applicable reference is made to appropriate research publications and relevant populations already explored in reference to the use of PAQLQ(S).

Table 7 indicates that in all seven schools there was a range of ethnic origins represented in each school participant group. Coding

for ethnic origin follows that used in the 2001 UK census and is the coding used in the National Pupil Database.

The subsequent immediate pages present the research data for consideration. Figures 24-30 inclusive indicate the PAQLQ(S) for each participant within each school.

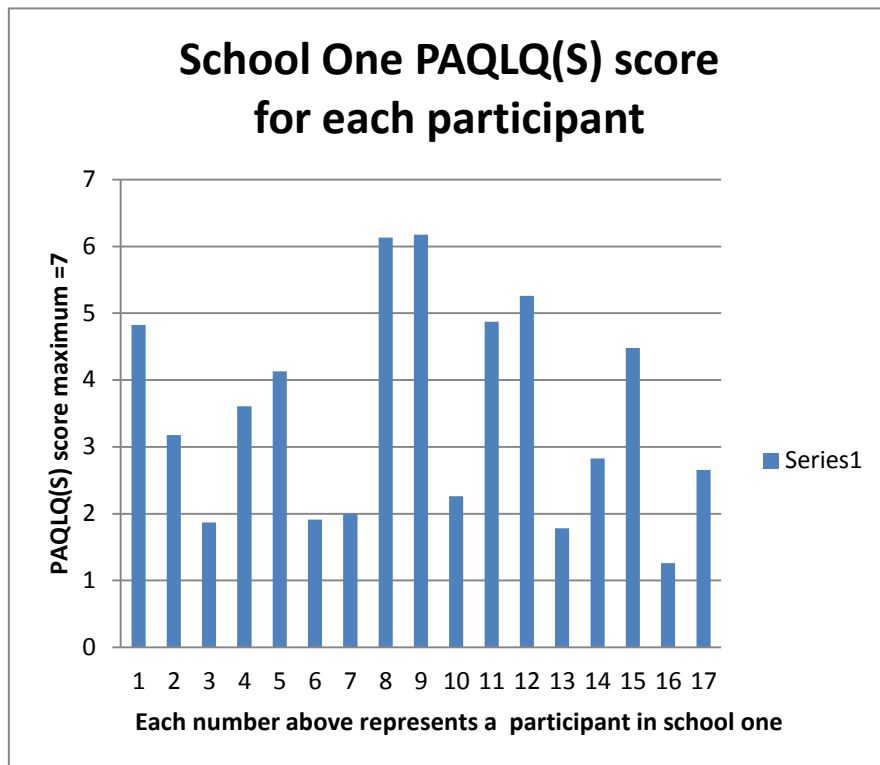


Figure 24: PAQLQ(S) score for each individual participant within school one.

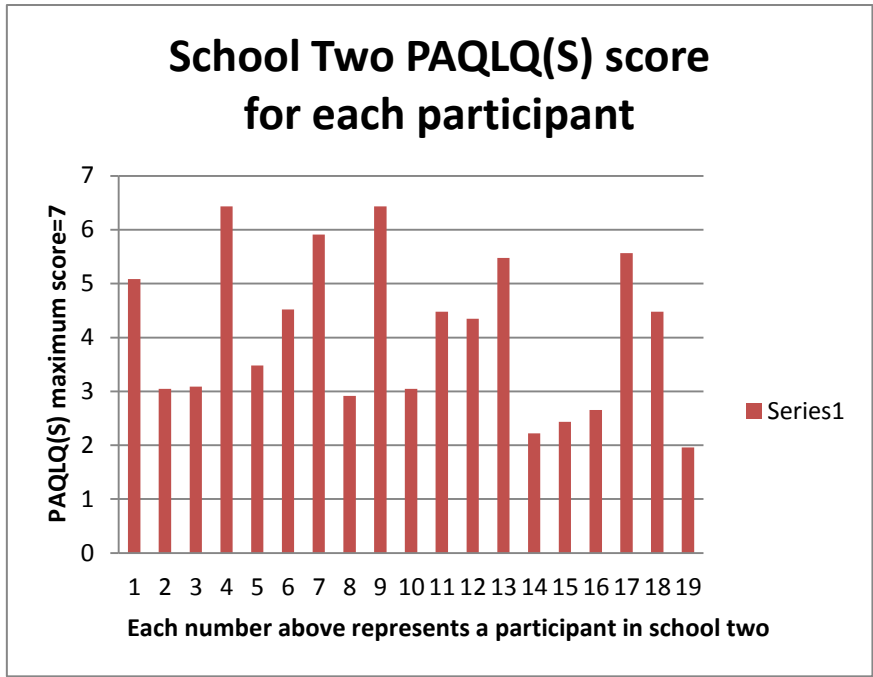


Figure 25: PAQLQ(S) score for each individual participant within school two.

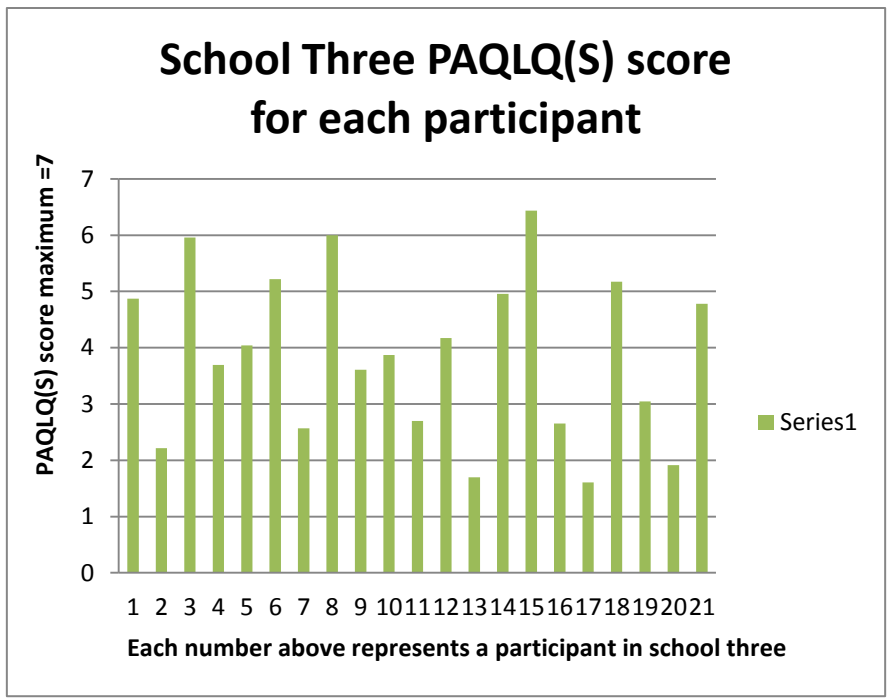


Figure 26: PAQLQ(S) score for each individual participant within school three.

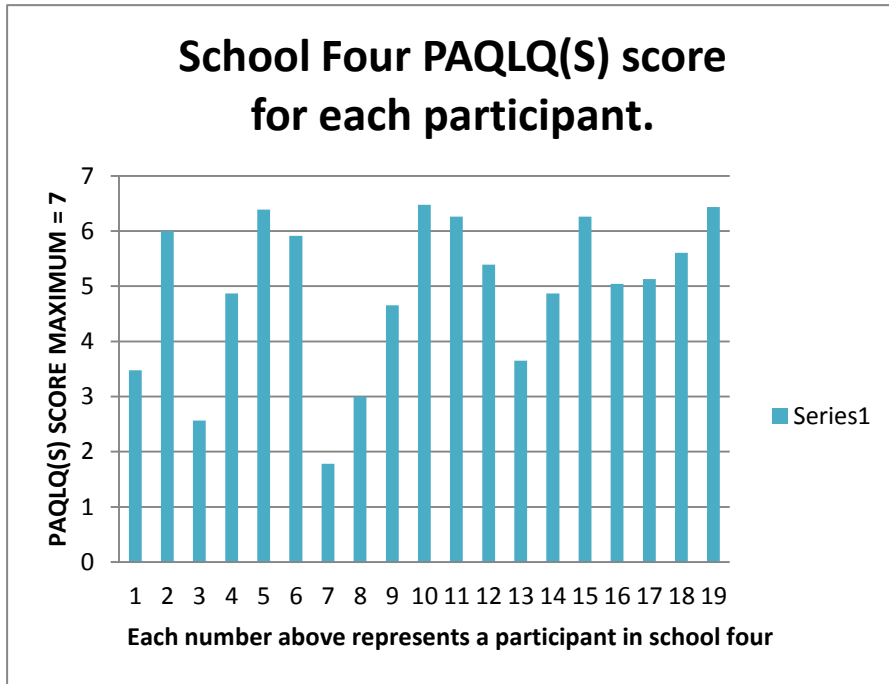


Figure 27: PAQLQ(S) score for each individual participant within school four.

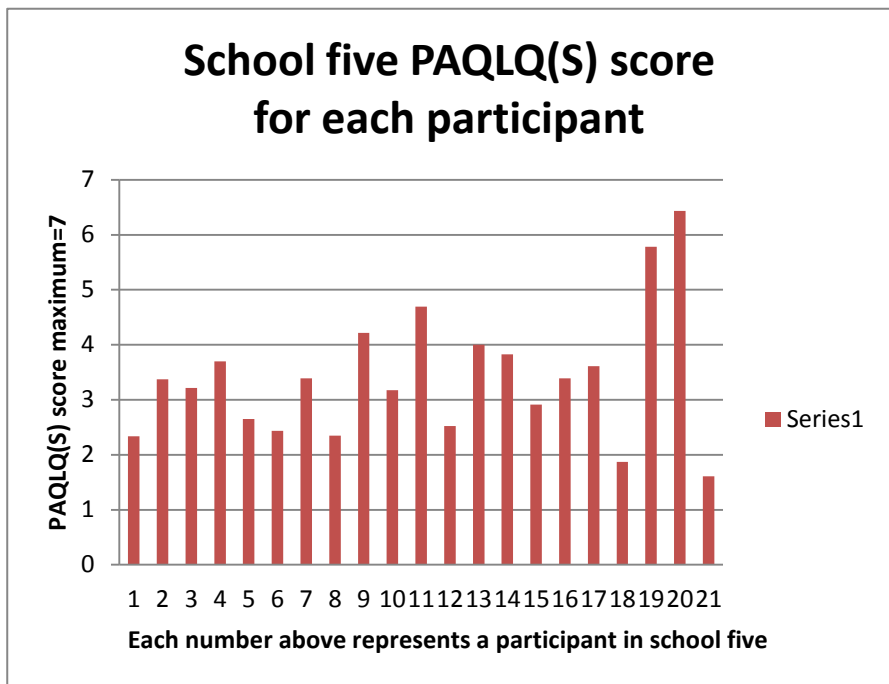


Figure 28: PAQLQ(S) score for each individual participant within school five.

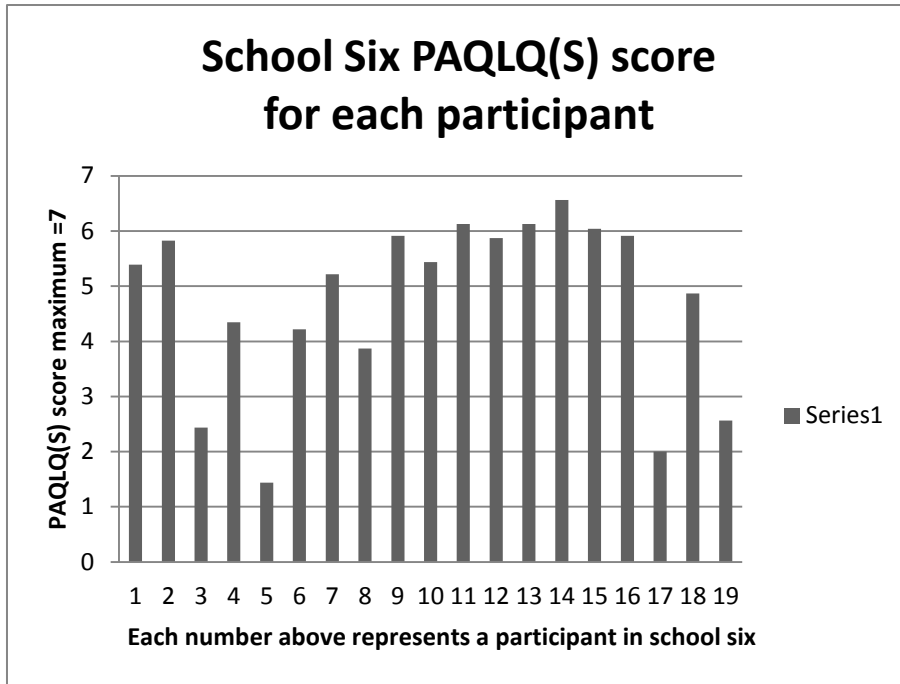


Figure 29: PAQLQ(S) score for each individual participant within school six.

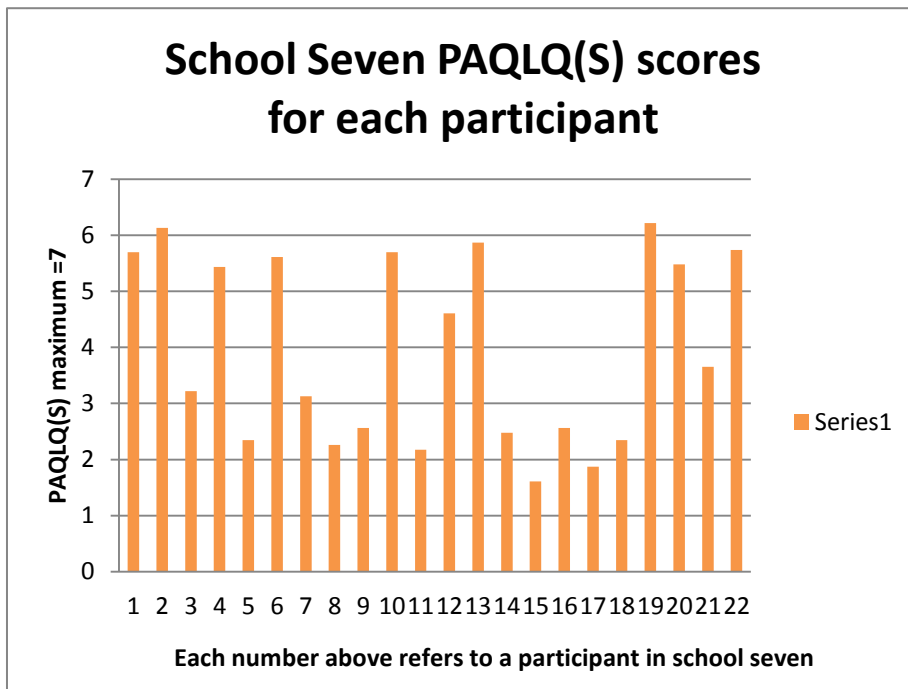


Figure 30: PAQLQ(S) score for each individual participant within school seven.

Initial consideration of figures 24-30 inclusive indicates that no participant achieved a score for their PAQLQ(S) of seven which would indicate that they perceived asthma affecting their quality of life. Rather every participant indicated that they perceived asthma affected in some aspect their quality of life, with the variation in score from 1.2 to 6.4 achieved across the data set of all of the schools.

7:5.3 Distribution of the range of PAQLQ(S) score across each school's research participants.

Table 8 summarizes notable characteristics of the PAQLQ(S) scores for all seven schools. The division between the PAQLQ(S) is based upon this researcher's understanding of the significance and relationship between symptom level and their clinical importance as indicated by the researcher's interpretation of the score by Juniper *et al.* (1996) and its relationship to asthma symptom level and disease management as indicated by the 2008 BTS/SIGN asthma guidelines. Juniper *et al.* indicates (recapitulating earlier text in this chapter- see section 7:3.7) that to interpret the score refer to either the blue or green card and use the words/ phrases associated with that numerical score. Thus a score of two or less reading the blue card indicates that the individual is very bothered by their asthma health related quality of life (asthma HRQoL), or reading the green card is affected most of the time by their asthma HRQoL. A score of 6 or more indicates from the blue card that the individual is hardly bothered at all by their asthma HRQoL, or hardly any of the time (reading the green card) affected by their asthma HRQoL. Clinically and in consideration of the aims of asthma treatment to ameliorate signs and symptoms and reduction in activities as a result of asthma the best outcome and the one that guides treatment is to not have asthma affecting any aspect of quality of life (BTS/SIGN 2008).

However, Juniper *et al.* (1999, 2004) suggest that the PAQLQ(S) can be expected to distinguish accurately children's perceived effects of asthma upon their HRQoL.

No. of participants	School one	School two	School three	School Four	School Five	School Six	School Seven
No. achieved score ≤ 2	5	1	3	1	2	2	2
No. achieved score ≥ 2.1 and ≤ 4	5	8	8	4	15	4	10
No. achieved score ≥ 4.1 and ≤ 6.0	5	8	8	9	3	11	8
No. achieved score ≥ 6.1	2	2	2	5	1	2	2
(check total number in school)	17	19	21	19	21	19	22

Table 8: Subdivision of PAQLQ(S) for each school.

Regarding Table 8 there are some noteworthy characteristics, these are:

- school one had nearly all its population of participants divided equally within the first three divisions of PAQLQ(S) score;
- school five had over 70% of its participants scoring between 2 and 4 in their PAQLQ(S) score;
- school six had 60% of its participants achieving a score of between 4 – 6 in their PAQLQ(S) score;
- school four had nearly 30% of its participants achieving a score of over 6 in their PAQLQ(S) score.

Consideration of the distribution of each school's PAQLQ(S) in Table 9 indicates the following population dynamics. Schools one, two, three, six and seven all achieved circa 10% of their research participants achieving a PAQLQ(S) score greater than or equal to 6.1. However school four had significantly higher percentage of its participants achieving a score greater than or equal to 6.1 at 21%. Conversely school five had only 5% of its population achieving this score range for PAQLQ(S).

Considering the range of scores available for PAQLQ(S) school five had over 80% of its population achieving a PAQLQ(S) score less than four. The next school to achieve similar results was school two which had 47% of its research respondents in the same categories as defined for school five in this paragraph.

7:5.4 Exploration of the variation in distribution of PAQLQ(S) between the schools.

Exploring this distribution of the range of scores for PAQLQ(S) and description of the data as above the following question can be asked, is

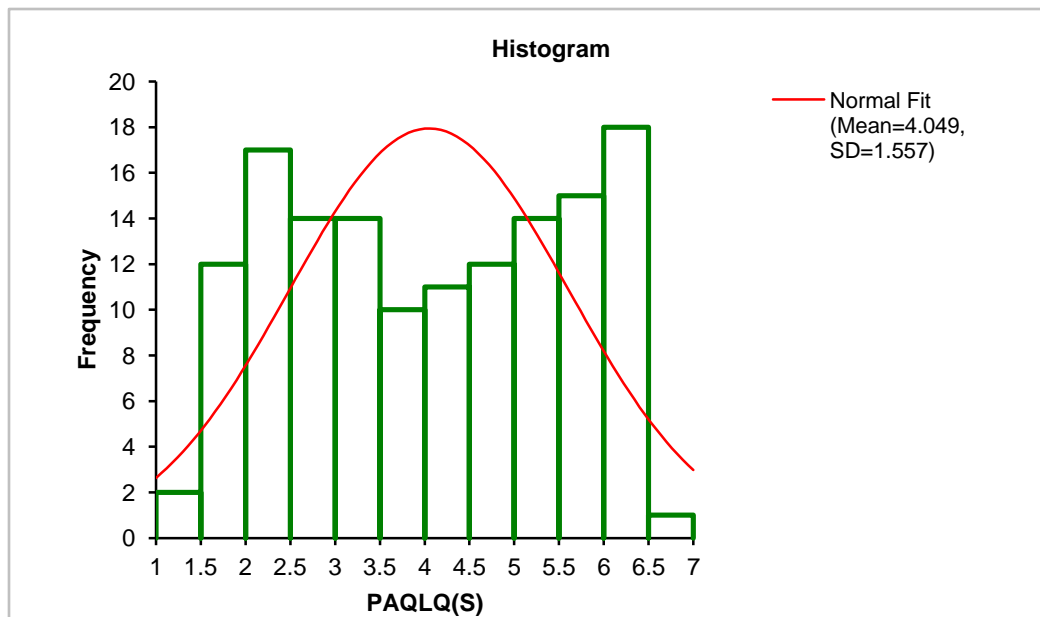
the distribution of the PAQLQ(S) scores into these ranks likely to have occurred by chance? *Id est* the null hypothesis is that the scores as ranked in this table occurred in this frequency purely by chance.

This was examined statistically utilizing Mann Whitney U tests, since Mann Whitney U tests assume that data can be ranked in an ordinal scale and does not assume normal distribution (discussed in section 7:5.5) of the data. Comparing the rank ordered distributions of PAQLQ(S) across each seven schools Mann Whitney U tests indicated that for all four researcher defined groups (PAQLQ(S) less than two, PAQLQ(S) greater than two but less than four, PAQLQ(S) greater than four but less than six and PAQLQ(S) greater than six) across and between each seven schools the distribution of PAQLQ(S) as ranked is statistically significant at critical values of $U = 0.05$. Thus it is possible to reject the null hypothesis which assumes that the distribution of these rankings occurred by chance and state that the distribution of these rankings is due to an effect of independent variable(s). The possible causal relationships between variables is extensive and expansive and unlikely to be limited to the influence of one variable in isolation, consequently these are not discussed in detail within this thesis.

7:5.5 What is the distribution of the total PAQLQ(S) research population scores?

From this initial early consideration of the results it is apparent that there is likely not to be a Normal distribution of the mean PAQLQ(S) score within each school, and also across all seven schools. This requires further consideration, since the interpretation of the data requires clear understanding of the mathematical conceptions inherent within any assumptions of analysis and statistical tests applied.

Plotting this data as distribution of the PAQLQ(S) scores (which is itself a mean score for each child) for each school together as one complete set of data reveals the following (figure 31), that the distribution of each individual participants PAQLQ(S) (138 in total) is not a good fit to the Normal Distribution.



Schematic indication of the division of PAQLQ(S) according to ranked data in intervals of 0.5 units, and the red line indicates the expected normal distribution for this data set and thus clearly identifies that this is not a normal distribution.

Figure 31: Schematic division of PAQLQ(S) scores.

Considering figure 31 gives rise to the noteworthy points listed below.

- If compared to Normal then distribution is skewed right (distribution is denser to the right of the mode than to the left and indeed the arithmetic mean is 4.05 which is to the right of the mode).

- Appears to be bi-modal. Note Bene - a modal point describes the "most common" value(s) or peaks in the distribution.
- Cluster points (or modal values) around 3.3 and 5.8 units (approximate values only)
- Thus does the population split into two easily distinguishable sub populations?

Consideration of figure 31 indicates clearly that the data does not follow a normal distribution. Thus any statistical test that requires normal distribution of data is not applicable to this data set.

7:5.6 The consequences of a data set that does not follow a normal distribution- how this data should then be analyzed.

The relatively low numbers participant in each school require some mathematical consideration, for example is it appropriate to calculate the overall school mean PAQLQ(S) and compare between and across each school? In consideration of this it is important to understand what occurs when the mean score of each school participant's PAQLQ(S) is generated, in effect what mathematically happens is there is the calculation of the mean of a mean. This allows the data to become more and more approximated to a normal distribution and thus is mathematically the first step in converting bimodal skewed data into a normal distribution and is thus valid (Bland 2003). This calculation is represented graphically in figure 32.

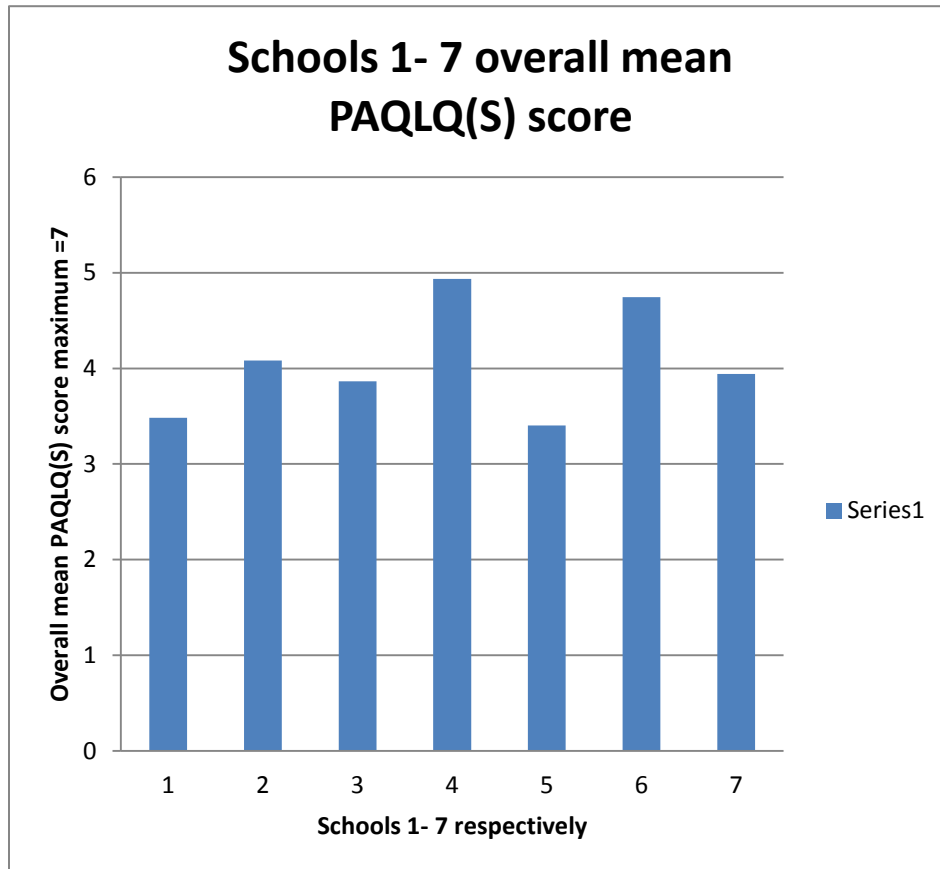


Figure 32: the school mean PAQLQ(S) score for each school.

It is not possible to calculate confidence intervals and apply other statistical descriptors to this data since it is known that the distribution of PAQLQ(S) does not follow that of Normal distribution. However, referring to the text presented earlier Juniper *et al.* (section 7:3.7i) state that a change of PAQLQ(S) score of 0.5 in the PAQLQ(S) known as Minimally Important Difference (MID) is an appropriate method to interpret the score (applied in longitudinal studies, but in the absence of any other aide to interpretation is adopted here). This is considered to be the change in PAQLQ(S) that is likely to result in a clinically significant change in asthma health related quality of life (HRQoL) warranting an alteration in anti-asthma treatment. It seems reasonable

mathematically to consider this MID in context to compare the overall means of all seven schools.

The question is: is there a difference in the overall mean PAQLQ(S) scores from each school? Figure 31 indicates that there is no significance (adopting the MID interpretation of PAQLQ(S) score) between schools one, two, three and five; and that there is no MID between schools four and six. However there is more than a 0.5 MID distinction between schools one, two, three and five compared with schools four and six.

7:5.7 Progress in chapter to date as outlined in initial paragraph, and the next key themes to be explored in this chapter.

At this point summary key characteristics of the initial PAQLQ(S) have been considered, indicating that all the children in the research population experienced in their perception some impairment in their asthma associated quality of life. That there is some variation between schools and this will be examined later. There is not a normal distribution to these responses and this limits statistical inference considerably.

In the final few sections of this chapter analysis will be presented relating to the domains of the PAQLQ(S), and their consideration in the context of this research. Concluding this some statistical inference will be made utilizing non parametric tests and their results discussed in context. This chapter concludes with a consideration of the methodological problems associated with the data collection, analysis and a critical review of the Juniper tool utilized to gather this data.

Ideally the aims of BTS/SIGN (2009) asthma treatment guidelines would be that all children with a diagnosis of asthma should have their asthma associated quality of life, such, that they perceive the affects of asthma upon their QoL to be minimal. Consequently it would be expected that it is more likely that children should achieve a QoL score greater than 6.0 for their perceived effects of asthma upon their quality of life. However, figures 24-30 indicate that most children in this research have not perceived their asthma to be minimally affecting their quality of life. Thus there is no weighting towards children achieving a PAQLQ(S) score greater than 6.0. This is a noteworthy observation.

Discussion now continues with consideration of the three sub domains of the PAQLQ(S) and a discussion of their value in data analysis. Following this a case will be presented to consider the relative merit and value of the PAQLQ(S) in gathering the research data, a discussion of its strengths and weaknesses and a discussion of its application to research in gathering asthma associated paediatric quality of life data.

7:6.1 Results from this data set for the three sub-domains of PAQLQ(S): symptoms; activity limitations and emotional affects.

It would not be possible to present the complete set of data for the three domains of the PAQLQ(S) obtained in the substantive text of this thesis. A summary of the results obtained are included in appendix ix. Overall summary data for these three domains are presented below.

The three sub domains for each research participant follow similarly along the same range of scores as their overall PAQLQ(S). *Id est*, if the overall research participant achieved a low PAQLQ(S) score, then the scores for the three sub domains would also be low. The converse is

also true. The three sub domains of the PAQLQ(S) are, symptoms, activity and emotional affects upon perceived quality of life.

Taking into account the data obtained from all seven schools produced the following mathematical and visual observation, there was a significant correlation between all three sub domains and also between any one sub domain and the mean score (PAQLQ(S)). Please see Table 9

	Mean (PAQLQ(S))	Activity	Symptom	Emotional
Mean (also known as the PAQLQ(S)).	1	0.928176	0.953267	0.878975
Activity	0.928176	1	0.871567	0.835702
Symptom	0.953267	0.871567	1	0.850442
Emotional	0.878975	0.835702	0.850442	1

Table 9: Correlation coefficients between the three PAQLQ(S) sub domains.

Juniper *et al.* (2004) present an argument that since asthma associated quality of life and this research questionnaire is not one-dimensional every question has value and should thus be included. (This argument is presented earlier in this chapter see section 7:3.7). Juniper *et al.* argue that the key tenets of their questionnaire and its use and value in QoL assessment are as summarized below:

- every question is important;
- and thus missing data can reduce significantly the impact or value of the completed questionnaire such that Juniper states she would not accept in her research any missing data from completed questionnaires;
- it should be expected that there is no correlation between any of the questions relating to different domains;
- and thus no correlation between scores/ answers for each of the three domains.

However, in this data set see Table 9 indicates that there was found to be a correlation between the three sub domains of the PAQLQ(S) and also the mean PAQLQ(S) score. In this context to generate Table 9 Pearson's Product Moment Correlation coefficient has been applied. This test was used and not the decision to use Spearman's coefficient since the question and interest focuses upon linear relationships between the data set. Note that Pearson's correlation coefficient has size 1 if and only if the two variables are (precisely) linear transformations of each other; this statement is true regardless of the distribution of the data set(s). Since a linear transformation would preserve the shape of a distribution. This is mathematically important to maintain when there is a diverse spread of a data across a large population. Also it is important to recall also that the smallest size of the coefficient is 0 and this usually occurs when the two data sets are independent (i.e. completely unconnected), however this is not necessary to consider further here.

Realistically, it is hoped that there will be a coefficient close to 1, indicating the data sets are a linear transformation of each other +/- a random error term with small variance. That is exactly what is needed to be considered and proven in order to know and be certain that the distributions are all similar, so Pearson's coefficient is an ideal and convenient tool here. The final caveat to this paragraph is the acknowledgment that there is a statistical test for correlation that uses the Pearson correlation coefficient and produces p-values. However this demands a Normal distribution, anyway since the data set indicates there is not a good fit to the Normal, p-values cannot be calculated this way.

It is possible to consider if required to state (accurate) p-values for the existence of a correlation, using Spearman's Rank correlation coefficient would be a better tool. Thus a thorough and formal correlation analysis

may use both Spearman's and Pearson's methods – but this is not considered further in this chapter since Pearson's rank correlation is more than sufficient to address the concerns and questions arising in this chapter.

Consideration of Table 9 reveals that in the context of correlation between the three domains the following statements can be made.

- As expected mathematically, correlation coefficients are high (0.9) between the mean PAQLQ score and any sub-domain PAQLQ score. Why was this expected? Since because about one-third of the Mean PAQLQ is exactly that of the sub-domain score.
- As a result of point 1 above, the distributions of any PAQLQ sub-domain are similar (in shape) to that of the Mean PAQLQ. In particular they are not a good fit to the Normal distribution.
- There is an indication of correlations between all sub-domain scores. For example, high Emotional PAQLQ is associated with high Activity PAQLQ score.

As illustrated by the above summaries, a correlation between sub-domain scores does suggest that a level of internal consistency, or redundancy, exists in the questionnaire. For example, Activity PAQLQ and Symptom PAQLQ scores are statistically similar, thus it is worth considering if it would be possible to avoid the 'bother' of asking both sets of questions.

7:6.2 Discussion of the consequences of a correlation between all three sub domains and PAQLQ(S) apparent within this data set.

Considering this powerful correlation between all three PAQLQ(S) sub domains this does not appear to be clinically incongruous with the known association between disease pathology and effects upon physiological functioning. For example, experiencing symptoms of asthma such as breathlessness and wheezing which occur daily would reduce physiological ability to participate in sports and associated activities. Thus there should be a positive and statistical significant correlation between symptoms of asthma and ability to participate in daily activities.

These should be expected, since the age range that this questionnaire was given to in this thesis ranged from seven to eleven years. In this age range it is important to participate in activities with peers, to be valued, and similar within a peer friendship group (see chapter two) should not be underestimated. Thus any factor which makes one individual different from another can cause and would be expected to cause emotional affects, plus the additional influence that these children discuss in their interviews (qualitative data) concerning the emotional affects of managing their asthma in school suggests that this correlation too should be expected.

At this point the following has been discussed in this chapter, as outlined in the introduction paragraph. The rationale and method adopted for the data collection has been presented. The overall obtained QoL data has been explored, the distribution of this data has been discussed. Consideration has been given to the variation in school population mean PAQLQ(S) and individual participant PAQLQ(S) score. Statistical analysis has been applied to describe the data set more fully, considering the possible reasons for the distribution of this data. Furthermore, the highly statistical significance in correlation between the three sub domains of the PAQLQ(S),

emotional, activity and symptom domains has been described and explained in the context of this data set. The next section in this chapter will explore how the data analysis and observation of the correlations presented in Table 13 present a challenge to the use of and interpretation of the PAQLQ(S) questionnaire.

7:7 Consideration of the use of PAQLQ(S) and its methodological limitations in this research context.

The consideration to use Juniper *et al.* (1999, 2004) PAQLQ(S) questionnaire is presented earlier in this chapter. However, throughout the analysis of this data methodological problems relating to analysis of this questionnaire have arisen which have caused significant problems in exploring the data set. These were not foreseen when the decision to utilize Juniper *et al.* PAQLQ(S) was made and will be discussed more fully below.

Juniper *et al.* state that when they piloted and validated their questionnaire children over the age of seven could comprehend and appropriately select their response to the questions. Selecting a phrase and thus an associated numerical score to signify their response. However, reading more fully the appropriate supporting information relating to the use of the PAQLQ(S) questionnaire validation and cross referencing this questionnaire and comprehension by children utilized 1000 children. Whilst this is certainly a large number of children to pilot and validate a questionnaire for initial publication and use of the questionnaire in 1996, subsequent work has related to translation of the questionnaire into many languages rather than focused continued validation of the questionnaire per se.

In the gathering of this research data many children found it conceptually

very difficult to distinguish the slight nuances associated in the choice of phrases, for example the difference between 'somewhat bothered' and 'bothered a bit'. This was not expected to be a methodological issue encountered in this research. The wide use of the PAQLQ(S) questionnaire in anti asthma medication trials does not mention any conceptual problems encountered by the research respondents. Neither do Juniper *et al.* (1999, 2004) in their defence of the questionnaire allude more to conceptual problems apart from that summarized above. However, in this research 102 children from 138 asked for help to understand what was meant by the words in the selection of their responses to the questions.

The method of data analysis to obtain the mean PAQLQ(S) score and the three sub domains of symptoms, activity and emotional domains suggests that it is possible to utilize wide ranging statistical analysis to explore the data set obtained, using parametric statistical data analysis methods, and thus make statements that can be more widely applied and potentially made generally to a whole population for example Shedd *et al.* 2007, Snow *et al.* 2005, Sawyer *et al.* 2001, Cuijpers *et al.* 1994.

For the PAQLQ(S) the choice of responses for any question is either from the green or blue card which contain a selection of responses against which numerical values are applied. Although there are numerical values applied to the questionnaire responses, these only give the data set ordinal ranking following the now accepted theory of Smith Stevens (1946) associated with scale measurement and rankings. Ordinal ranking scale allow data only to be ranked in order, it does not provide information relating to size of division between each ranking in the scale and conveys nothing indicating exactly what is being measured and the characteristics of the ranking of the data. Utilizing ordinal scales in pure mathematical terms allows only descriptive statistics to be applied, these are usually limited to means, percentiles and the limited use of non parametric

statistical tests although consideration to the use of these needs to be given (Bland 2003).

It is clear when considering the choice of written responses in the PAQLQ(S) that this is an example of an ordinal scale only. For example in the PAQLQ(S) there cannot be applied and assumed to be the same numerical difference between statement numbers 2 and 3 as statements numbered 4 and 5 on either the green or blue cards.

Furthermore, Juniper *et al.* (1999, 2004) state that every question is important and should be completed. However, in this data set there was a high correlation between all three sub domains, to the extent that it would be possible in this data set to only ask questions pertaining to symptoms and from this obtain a score for the other three domains. This would suggest that in the context of this data set Juniper's claims that all 23 of the questions are essential and must thus be asked, is not true here. It is worth considering for future use if just asking three questions pertaining to emotional affects of asthma, symptoms and activities will be sufficient to generate a measure of asthma associated quality of life as indicated by the value of PAQLQ(S).

Thus in the context of this data obtained from 138 research participants some attention needs to be given to the three points listed below.

- Is there any validity in using the PAQLQ(S)?
- Is there any need to calculate all three sub domains as distinct components of the PAQLQ(S) score?
- Do all 23 questions need to be asked?

The PAQLQ(S) certainly had for this research methodological problems associated with it. These included conceptual problems with children trying to identify their correct responses between very similar wording

which would tax many adults understanding. There is also for some researchers the tendency to assume that the responses are generating both interval and nominal data, as a consequence of how the questionnaire responses are portrayed.

However, considering the interpretation of the actual PAQLQ(S) score and considering this in the context of the qualitative phase of this research it would appear that the range of scores obtained relate well to the type of information the children were stating in their interviews. Comparing individual respondent PAQLQ(S) scores with their narratives and visual art work generates comparable agreement across these types of data, generating argument in support of utilizing mixed methodology to explore this topic.

Thus although interpretation and selection of their responses certainly proved difficult for some research participants and they stated this in the selection of their responses at the time asking for clarification relating to the wording (which could not be supplied). Perhaps some responses might have been incorrectly given and a response ranked lower or higher than the one that they were intending to give recorded. However, broadly considering how the score for PAQLQ(S) compared with interview data; there was generally consensus between how the children felt and perceived the effects of their asthma upon their quality of life and the signs and symptoms they discussed in their interviews.

7:7.1 A discussion of the merits of asking all 23 questions in the PAQLQ(S).

The three sub domains have been calculated for this data set but this does not add any significant information pertaining to how children's perception of asthma varies depending upon what aspect of their life they are considering. Since for this data there is a strong correlation between any of

the three domains and thus calculating one will allow the derivation of a statistically significant (and numerically almost and in some cases an identical) score for the remaining two. This implies that in the consideration of this data set for this questionnaire completing all 23 questions was not required.

In connection with this thesis and data set there is a correlation between disease specific quality of life measure and socioeconomic variables and school specific factors. Considering the claims that asthma is a multi dimensional disease with affects upon quality of life that are measurable by multi dimensional QoL tool such as the PAQLQ(S) is not upheld in this data. In contrast this data set has revealed that asthma perceived effects upon children's QoL is available and interpreted in this data set as only one score the PAQLQ(S) and the three sub domains do not reveal any significant variation in the scores from the participant's overall PAQLQ(S) score. This indicates that for the children in this data set the effects of asthma is similar upon their QoL regardless of which three sub domains are considered, or the overall PAQLQ(S).

In conclusion the data presented within this chapter indicates that asthma significantly affects children's perception of their PAQLQ(S) with all research participants indicating that asthma affects their daily activities. This indicates that for the 138 children in this phase of the research the aims of asthma management (to have no asthma associated symptoms, and restriction upon daily activities) according to the BTS (2009) and global asthma management policies have not been met. Furthermore, for fifty percent of this population their perception was that they had asthma associated symptoms affecting their quality of life on most days of the preceding week.

Utilizing the PAQLQ(S) as the tool to assess the association between

asthma and its influence upon quality of life has not been without methodological challenges. These have been discussed where appropriate throughout this chapter.

7:8 Chapter summary.

All 138 children with asthma in this stage of the research perceive that asthma does have an influence upon their quality of life. In some schools this is more adversely perceived than in others, there is a link between children educated in schools located in lower socioeconomic settings achieving low scores for their asthma associated quality of life.

Children with asthma feel that their asthma affects them similarly in all three sub domains assessed in the PAQLQ(S), emotional affects, effect upon activity and level of symptoms experienced. This correlates well with the qualitative focussed data discussed in earlier chapters and will be considered further in the final chapter of this thesis.

8: Appreciating the results (a synthesized picture): a portrayal of two schools.

8:1 Chapter outline.

This chapter will provide an example of the approach used in the synthesis of the data obtained in this research. It will present and then compare the data obtained from two schools using both the qualitative and quantitative data to illustrate this comparison. This will generate a picture of what it is like to manage asthma in these two schools, and answer the key research questions.

8:2 Factors considered in the selection of two schools.

Seven schools are considered in total in this thesis, (see section 3:8.9i). From these seven schools two are considered in this chapter. The choice of which two schools to discuss was made in order to have schools representing the widest range of characteristics considered in the school selection research inclusion criteria. The consideration of socioeconomic factors in the choice of which two schools is discussed further.

The seven schools are in varying socioeconomic areas. In this chapter the school from the area of least deprivation, school seven is selected for inclusion and discussion since this school is the only one in this category, compared with school two which is one of the three from an area of high socioeconomic deprivation. School seven had a written asthma policy (it is referred to as school A in chapter five) and it is the only school discussed in this thesis with a school asthma policy. School two was chosen rather than school three and six which are, in terms of socioeconomic data (see Table 10) similar, since it had other characteristics considered as important in the research data inclusion criteria. For example its geographical location, school two was eight miles away from school seven and thus not likely to have children (siblings) from the same family attending both schools. Whereas school three was only two miles from school seven and it might be possible that siblings from the same family could attend school seven and school three.

Choosing school seven and two was made to explore any difference arising from the differing geographical area, and socioeconomic influences impinging upon both schools. It may allow for example a discussion of the inverse care law (Hart 1971) and socioeconomic factors in the context of childhood respiratory health care. That may be explained to be as a result of the known inverse care law (discussed in the literature review).

The two schools also had differing pupil and physical properties, school seven was a junior school (thus pupils were in years three to six), whereas school two was a primary school (thus pupils from reception to year six). Although the child related data discussed only refers to children from school years three to six, the size and premises of the school buildings influences access to school staff, ease of movement around the school property and outside space that the children can play

in. These were discussed as themes in the children's interviews (see chapter six). School two was oversubscribed by 52 pupils; this was 25% more pupils than the school (according to LEA license and DfE inspection) was equipped to provide education for, and thus the school staff and pupils were likely to have had pressures put upon them in respect to number of pupils in the classroom, access to play areas, and provision of teaching resources which may have influenced their ability to cope with and acquire knowledge of pupil chronic health needs. School seven was in comparison under subscribed by 12 pupils (20%), and this might have allowed school staff for example, more time to consider in greater detail the health needs of their pupils.

8:3 How the research data is considered together in this chapter.

This chapter will provide an overview of how synthesis of the data occurred in connection with the research aim (see section 2:6.4). This was undertaken by the researcher considering together all the research data via a process comparable to pouring through a funnel (the synthesis process) a number of ingredients which individually give a flavour of what is to come but which when together generate a taste (the picture of asthma management) far deeper than the individual parts (see Figure 33). All the data that was obtained relating to school two and school seven from children and school staff are considered together in this chapter, with equal value placed upon each of the data sources. No data is discarded in the consideration of the research questions and the overall summaries represent an attempt to portray what it was like to have and manage asthma in the two schools in the school year 2008 - 2009.

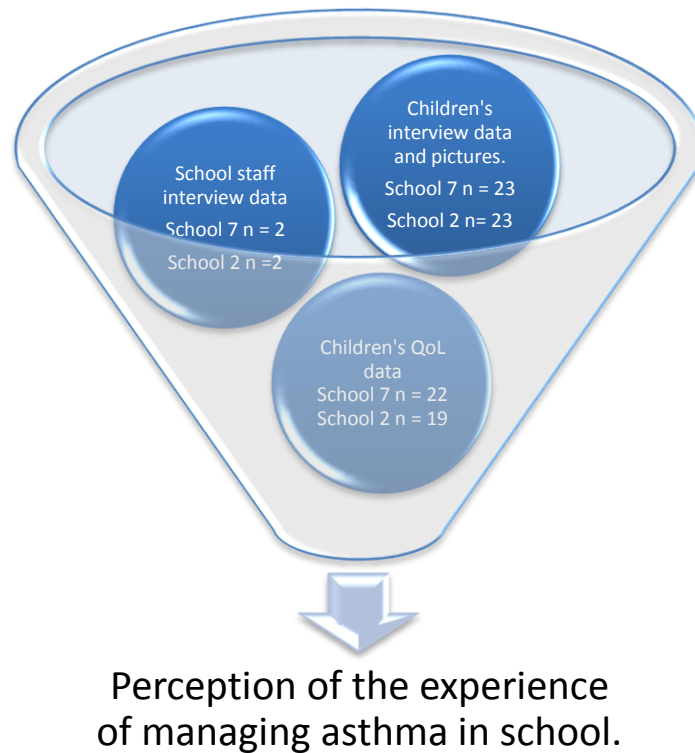


Figure 33: Consideration of the research data.

Characteristics of schools two and seven are listed in detail in chapters three, four, six and seven of this thesis. However to aid recall and data assimilation in the context of this chapter the key information is presented in section 8.4.

8:4 Summary characteristics of school seven and school two.

8:4.1 School Seven.

This school had 227 pupils on its school role in 2008. It was undersubscribed by a total of 12 places. The 2008 mean weekly income was £610 for the geographical ward in which it was situated, and it had 84% of the eligible population (excluding people retired and claiming pensions, those on long term disability benefits) in full time work . School seven had a very brief asthma policy it is referred to as School A in chapter five.

8:4.2 School Two.

This school had 262 pupils on its school role in 2008, it was oversubscribed by a total of 52 pupils. Mean weekly income was £470 for its geographical ward in which the school was situated in 2008, and it had 38% of the eligible population (excluding people retired and claiming pensions, those on long term disability benefits) population in full time work. School two did not have a school asthma policy.

8:5 The experiences of staff managing asthma in school seven.

In this school two members of school staff were interviewed (refer to figure 11; section 3:8). The qualified class teacher is referred to as 13S in chapter four, and the school meal assistant is referred to as 8S.

School staff reported that they felt prepared to manage asthma in school and knew what to do should a child become unwell. However, they still asked for additional advice and training and acknowledged that the information that they had gleaned had been in the past and needed to be updated. The quote below is from a qualified teacher in school seven, who volunteered a significant amount of information concerning her knowledge of asthma, some is correct but not all. This quote is one of the longest obtained without prompts to the question 'how do you manage asthma in school?'

13S: "We've had a couple of, you know the half 'in service' days for medical conditions, so its been quite general. So in terms of asthma just a very minor little bit about trying to calm the child down and trying to talk them through so the breathing comes and then if it's not getting much better, try the paper bag, just to try the inhaling and the exhaling and just calm it down and that if we feel that it's more prevalent than that and we know that children have greater degrees of asthma within school, then we phone home and check with the parents what they would like to come and do, but my own training has been very much just what I've learned on the job from many 'in service' days and just having friends at school who'd had it and how they'd managed.

Stating in this interview concerning pupil access to medication:

10S: "In the school, we sort of well you know we get it sorted and we have experience of it you see. The children have their inhalers with them and we let them use them whenever they need and that you see is good, they [children] don't have to think where is their inhalers and panic. They just get them when they need them and that's good."

A school meal time assistant (SMA) who was interviewed with Teacher 10S stated:

8S: "Well... its like this, I just let them do what they want when they're outside, it is helpful you know they can come and go when they like

and get their stuff [medication] from the class. They like the woods... that's a good place and I check that they are OK, but often that's all they need just chance to go and sit down."

The staff in this school indicated that they allowed children with asthma access to their medication [inhalers] when required relatively easily. There was provided a quiet area outside for children to sit in [the woods] which during lunch time was checked upon by school meal assistants.

School staff indicated that they would have liked to know more about asthma and its management. However, they had some knowledge already which they felt provided a good basis for their decisions and management.

10S: "You know, I would like to know more about it [asthma], I'm not sure how it is sort of sort of well managed and that, and I don't know the names or anything.It would be good to know more...and have it in school so we could find it easy like to understand how it is done."

8S: "I don't know how it is done, like you know. I don't know about the breathing in and out stuff.... I don't mind, I don't mind think it should be like out of their mouth when its going in... you know the smoke stuff but I don't like, I don't like -think that its ok but who do I ask about it?"

The school staff reported that they had tried to adopt a positive attitude to the management of asthma and to ensure that all children felt valued in school. Undertaking this by a system of school staff that were identified by house groups that allowed children to talk to other staff members as well as their class teachers.

10S: ".....and we have a house group system, so our children get separated up into year groups, mixed around and they meet other adults every fortnight for a 'circle time'. So they know at least one other adult quite well. Hopefully to install confidence to go and have a

conversation with them if they feel they can't talk to the class teacher."

Communication appeared to occur quite openly between the school staff and parents/ carers of children, often informally.

10S: "we're quite informal on meeting out on the playground beginning at start of days and parents feel quite comfortable just popping a note in or phoning up."

It appeared that the school staff managed pupil asthma by allowing children free access to their medication, they felt that they knew enough about asthma and its management to allow children to use their medication but would have liked to know more. School staff talked quite freely about their management of pupil asthma, they cited positive attitudes towards children with asthma and allowed the children to decide when they needed their medication and opportunities to rest. The school premises provided opportunities and space for children to sit quietly and rest.

Neither member of school staff discussed particular problems or poor experiences of managing pupil asthma in this school. Instead they discussed how they felt asthma was reasonably well managed in this school.

8:6 Views and experiences of children in school seven.

In this school 23 children participated in the qualitative phase of this research, discussing their asthma and generating art work. The decision

has been taken to identify the children using a different style than that used in chapter six, this is because using numbers and footnotes to distinguish ages and schools for the children's quotes worked well in chapter six as a rapid assessment of the type and variety of quotes provided. However, in this chapter it was felt to be important to identify the children more fully and this included their gender, thus allowing the reader to get a better sense of how the quotes interrelated and whether or not there was gender difference.

These school children used positive words and phrases to indicate how they felt about the way their asthma was managed in school.

“No, there's nothing that they could do better or different, yep...I think its ok.”

Girl S aged 9

“I think its great, its much better than school y [infant school which feeds into school seven]. We have our inhalers with us in the class and we can use it when we need. I just go and get it when I need to and I walk in. That's good and no one asks me why so its great. My friends they still stare at me, so I go away” Boy W aged 10.

“Well, something's are not good, I don't like my friends staring at me and feeling different. But I can talk to Miss X [teacher] about that and it helps. And 'cos my friends who know I have asthma feel like this then its great and I can use them to help me so that's good” Girl Q aged 7

“ You know most of them [teachers] are okay, they don't understand it but they let me get on with things just the same.... so I go in and get my stuff [medication- inhalers] and then leave it.....”

Mr XXXX he shouts if he thinks you are dawdling but the rest are okay”. Boy H aged 9

Furthermore, children reported that they found having somewhere quiet to go when outside playing was useful, that they liked being able to sit down and think and one child drew the outside quiet space.

“I am trying to draw the quiet area and me sitting down on a bench to try and show that I am resting.” Boy B aged 9

“ I can sit down whenever, not just in the quiet area I can sit down in the class room, or in the gym.” Girl A aged 7

Similarly the children in this school reported that they knew where their inhalers were kept, in their class room and could access them whenever they needed. However, one child had his inhalers with him in his bag and this caused the other children to comment that he should not have his medication actually with him. He should just be able to get it when he needed.

“ You shouldn’t have that!” Girl D aged 11.

“ Yeh...my mum says I have to have it cause I get so ill and its helpful....thats what I like having my inhaler with me.....” Boy E aged 10

CF...How do you feel about that?

“ Well I keep it quiet and use it like.....” Boy E aged 10

In this school some children tried to explain what asthma was, stating that it was to do with the air, and their breathing but were unclear how exactly it occurred and what their medication did.

“Miss, you see my inhaler it works to stop the air from getting in, and then when the bad air can’t get in I don’t get it..” Boy E aged 10.

“It’s this, its the snot and then I’am sick and I’am better and that’s good you see I’am better then and that’s good when the snot is out”
Girl F aged 8.

8:8 Quantitative data, Quality of Life (PAQLQ(S)) scores for children in school seven.

This section examines the perceived effects of asthma upon the children’s quality of life in school seven. Relevant PAQLQ(S) data (obtained from completing Juniper *et al.* (1999) asthma specific quality of life questionnaire) considered in chapter seven will be presented in connection with this school and suitable additional detail will be given as required.

School seven’s pupils with asthma perceived that their symptoms of asthma affected their quality of life such that (refer to Table 10) 55% of them had symptoms of asthma that affected them on most days (according to the interpretation of PAQLQ(S) score as suggested by Juniper *et al.* 1999).

School Seven number of pupils with asthma in this school research data set achieving this PAQLQ(S) score. N=22	PAQLQ (S) score
2	≤2
10	≥2.1 and ≤ 4.0
8	≥ 4.1 and ≤ 6.0
2	≥6.1 and ≤ 7.0

Table 10: Summary data from children in school seven relating to their PAQLQ(S) score.

Table 10 above indicates that the same number of pupils (two) achieved the lowest score (of less than or equal to 2) for their PAQLQ(S) as those that achieved the highest score (of greater than or equal to 6.1). A score of less than 2 indicates that every day asthma symptoms and signs were significantly limiting children’s activities and engagement in daily life which the children perceived as affecting them significantly. Similarly, two children perceived that their asthma and its signs and symptoms was not significantly affecting their engagement with daily life.

More than 50% of children in school seven achieved an overall PAQLQ(S) of less than 4.0. Interpretation of this figure using Juniper *et al.* (1999) guidance indicates that these children perceived that their asthma affected them ranging from ‘some of the time’ to ‘all of the time’. Furthermore, that they felt ‘somewhat bothered’ by this to ‘extremely bothered’ by their asthma.

Considering the three sub domains associated with the PAQLQ(S), these are symptoms, activity and emotional affects upon perceived

quality of life. Generates the following information (refer to Table 11), it remains true that there is a good correlation between all three sub-domains as presented in chapter seven.

Mean score	Sub-domain	Range in score, minimum – maximum value
3.66	Symptoms	1.6 - 6.5
3.82	Activity	1.8 – 6.2
3.87	Emotional Affects	1.5- 6.2

Table 11: PAQLQ(S) three sub-domains for school seven.

Scores for the children in school seven are (n =22):

This indicates that the children in school seven perceived that they were affected by their asthma in all three of the sub domains as above.

Examining the mean values for each sub-domain no one sub-domain is more affected than any other in school seven. The mean values for all the sub-domains indicates that for the 22 children who participated in this stage of the research their average perception was that:

- they had some degree of restriction upon their activities in the week;
- experienced on some days of the week asthma symptoms ;
- and that they had for a few days a week a reduction in their emotional stability because of their asthma.

8.8 The experiences of school staff in school two.

Similarly as in school seven only two school staff were interviewed, one was the deputy head teacher, referred to as 11s in chapter four and the other the school first aider referred to as 6S.

School staff in this school appeared less clear about their knowledge of asthma and its management in school.

Deputy head 11S (whom himself has asthma) replies to the question how does he manage asthma in school:

11S: “it’s quite strange actually because em.....unless you’re the qualified em...first aider, it sort of takes all that is taken away from you, So 6S: she’s our qualified first aiders so they are the people who make those decisions. Ummmm.....but the most important thing usually is if a child’s got particularly bad asthma or whatever is that you make sure they’ve got easy access to it [inhaler] during playtime or things like that, but then they still usually have to see a first aider.”

6S: “I didn’t actually have em...official training, I just....because I’d been here for so long when I first came I was just told to you know give them two puffs and they would get on with it and at that point we were having er, we had I think it must have had about 15 children every lunch time for two classes before they went out to play....but now I just ask do you really need it and most of the time I make them wait and I say ok only if its still tight do you need it.”

Staff in school two reported that they were unclear regarding where inhalers were kept in the school.

11S “ I think they’re kept in the class rooms, yes I am sure they are since they should be there for children and yes...but I know that

they're not in Mr S' cupboard when I teach for him, or in Mrs P's cupboard so I guess.....erm I guess that they are not always there and I, I uh I don't know where they are then."

6S: "they are in the class rooms, but no I have some, I have child A, B, C.....at least but then I don't know if they are with me or in the office, perhaps they are in the office and that's the reason for it."

Both school staff interviewed in this school indicated that they would have liked to know more about asthma and its management in school.

11s: " I'd like to know how they get asthma, and why its more of a problem, you see I don't remember it being a problem when I was at school so something's changed... I like to know about in a school training day but we don't get it very often."

6S: "Yes, I've done the update last year and I think that I know it now....you see the trainer there said you need to know this and I do, but I can't remember how to do it and I would like to know more,....yes, I need to know more about it so I can understand."

Neither member of staff volunteered much information concerning the school atmosphere, or about communication between school staff and parents/ carers of children. The most information concerning this was revealed in the following quote.

11S : "because people are.....asthma is more common although diabetes is obviously on the rise and more children have asthma..... but maybe there is complacency around the whole asthma thing. Oh I've got asthma, sometimes it comes with a pump [inhaler], sometimes they don't , sometimes they don't bring....and even parental attitudes towards asthma I think at times it doesn't give you a full picture..."

School two's staff reported uncertainty regarding pupil asthma management, they were unclear where medication was kept in school

but were certain that the pupils do not have them in their possession. The first aider was not certain of how to manage asthma should a child become unwell and questioned in her interview whether or not medication should be given to a child who requests it, since in her opinion

6S: “children need it too much [salbutamol], I don’t think they need it so I ask them do you really need it and how will it make you feel? Let’s wait a while and after a few minutes if they’re breathing bad I go and get their medicine but they have to wait a few minutes at least five...”

The school staff were uncertain in their management of pupil asthma, they cited experiences of managing asthma which suggested that their feeling of discomfort hindered their decision making. The first aider choosing to deny access to medication immediately when children requested it, and both providing evidence that they didn’t actually know where children’s inhalers were in school should they need to access them. The school staff reported that they did not have open communication between them and parents/carers and the system for identifying children with asthma was limited.

8:9 Views and experiences of children in school two.

Similarly to school seven 23 children participated in this stage of the research, and the children are identified in a similar method to that used in section 8:5.3.

These school children spoke about the location of their medication in less certain terms. The following extract from a discussion with the children reveals the inconsistencies and uncertainties that the children felt.

“ Yes I have my inhaler in school.. we all do....” Boy AA aged 9

“ No we don’t I don’t have my inhaler in school, we’re not allowed to bring it in...your wrong...” Girl BB aged 10

“ yes I do we have it in the office...” Boy AA aged 9

“ no it isn’t it ‘s in the class room and I have mine I think in the classroom.” Boy CC aged 7

“ No we don’t we don’t have it in school its not to be in with us and instead we have to wait until we get home..” Girl DD aged 11

“you’re wrong its in school with us....I have mine.” Boy AA aged 9

Children in this school found that they were uncertain whom they should ask for advice regarding their medication or when feeling unwell in school.

“No,I don’t think I have anyone I would like to ask. No one knows and they all get it wrong so I ask my Mum.” Girl FF age 8

“Well... [firstaider 6S] she could help, but she tells me I don’t need it [inhaler] so I get it sorted by going to my friends and they have theirs in their pocket and I use it then, when no one is looking, thats what I do.” Boy GG age 11.

Taking the initiative and solving access to medication was indicated frequently by children in this school. Reporting that sometimes they used their parents medication when theirs had run out, or used friends when denied access in school.

Children reported that they wanted to sit down but had to achieve this by using other methods to allow them to sit. Such as asking for a drink of water, or needing to sit down to tie up shoe laces, or read a book.

“there’s no where to sit down, and we can’t when we are outside ‘cos we get shouted at so what we do is we get on with it and see what’s happening and then if its really bad we have a drink of water.... its

good now 'cos the water thing [water fountain] isn't working, so we have to go in get a cup and sit down. That's good and I can rest then." Girl HH age 10

"I, I'll do it different ,mind, I sit down in the hall and do my shoes and that takes ages so I gets me breath back and that works." Boy JJ age 8

Children drew pictures in this school that related to tasks of managing asthma and how they used their inhalers, they tended not to be able to provide an explanation for what asthma was and instead focussed upon what they needed to help them with it.

8:10 Quantitative data, Quality of Life (PAQLQ(S)) scores for children in school seven.

As discussed in section 8:7 this section represents data obtained from PAQLQ(S).

School two's pupils with asthma perceived that their symptoms of asthma affected their quality of life such that (refer to Table 12) just under 50% of them had symptoms of asthma that affected them on most days (according to the interpretation as suggested by Juniper *et al.* 1999).

School Two number of pupils with asthma in this school research data set achieving this PAQLQ(S) score. N= 19	PAQLQ (S) score
1	≤2
8	≥2.1 and ≤ 4.0
8	≥ 4.1 and ≤ 6.0
2	≥6.1 and ≤ 7.0

Table 12: Summary data from children in school seven relating to their PAQLQ(S) score.

Table 12 above indicates that just over half the children perceived that their asthma affected them ‘once in a while’ or that they were ‘bothered a bit’ according to their PAQLQ(S) score, achieving a score ≥ 4.1 . One child had a PAQLQ(S) score less than 2, indicating that they perceived that their asthma affected them ‘most of the time’.

Considering the three sub domains associated with the PAQLQ(S), these are symptoms, activity and emotional affects upon perceived quality of life. Generates the following information, it remains true that there is a good correlation between all three sub-domains as presented in chapter seven.

Mean score	Sub-domain	Range in score, minimum – maximum value
4.04	Symptoms	2 – 6.5
4.07	Activity	2 – 6.4
3.74	Emotional Affects	2.5- 5.6

Table 13: PAQLQ(S) three sub-domains for school seven

Scores for the children in school two are (n =19).

For children in school two it appeared that for them their mean scores for the three sub-domains of the PAQLQ(S) indicated that these children perceived they were less affected by their asthma symptoms and reduction upon their activities than they are the emotional affects of having asthma. For these children the mean sub-domain scores indicated that:

- children perceived that they occasionally had symptoms of asthma in the preceding week;
- occasionally in the preceding week that they had a reduction in their activities as a consequence of their asthma;
- frequently they experienced some emotional consequences of their asthma in the preceding week.

8:11 What it was like to manage asthma in schools seven and two.

This section will now present a synthesised picture of the experiences of both children and school staff managing asthma during the research data collection period.

Both school seven's and two's children scored very similar PAQLQ(S) values, with both the overall school mean PAQLQ(S) score and the individual three sub-domains achieving similarly results as perceived by the children. This would indicate that in these two schools children perceived that their asthma affects them similarly as assessed by the PAQLQ(S). For the majority of children in both schools, they perceived that their asthma was limiting their participation in activities. For over 50% of the children in both schools asthma was bothering them 'some of the time' and for 15% of the children it was bothering them 'most of the time'.

Regarding the effects of asthma upon particular domains within the PAQLQ(S), in respect to emotional function there was a striking difference between schools two and seven. School two's pupils had the narrowest range between 2.5 -5.6 (range of 3.1) in comparison with school seven's pupils range of 1.5 -6.2 (range of 4.7). It appears from these figures that children in both schools perceived that asthma affected their emotional well being, but that children in school two perceived this effect at a more consistent level, in similar terms to each other whereas children in school seven had the wider variation in how they perceived this effect. School seven's pupils had a lower score for the perceived affect of asthma upon their emotional well being, and also higher scores for their emotional well being in comparison with school two.

All pupils perceived reviewing the mean scores for activity limitations that this happened 'quite often', *id est* that their asthma quite often limited their activities in school. They also perceived that the symptoms of asthma 'somewhat bothered them' and that this occurred with comparable frequency in the school week as the asthma associated reduction in activity limitations. It would appear from the data that children in school seven perceived that they had slightly more reductions in their activities compared to children in school two. In summary according to the PAQLQ(S) information, children in school two had asthma that they perceived was less bothersome (considering the overall PAQLQ(S) score and three sub-domains) to them than children in school seven.

However, the school staff in school seven spoke positively about the management of asthma and its treatment in school. They stated that they knew enough to manage it within their school, they would have liked to know more but that they generally felt prepared to manage asthma in their pupils. The school staff acknowledged that they had some formal training in the management of asthma and were aware of the school policy concerning access to asthma medication. They remarked upon the communication strategies that they had in place both between parents/ carers and the children and felt that these worked well. The school allowed children easy access to their medication [inhalers] and all the children knew how to get their medication. This school did have a school asthma policy, which although it was a brief document indicated clearly where medication should be stored and how common anti asthma medication worked.

Staff in school two in contrast did not know where pupils' inhalers were kept, they did not feel confident in their knowledge concerning the management of asthma and asthmatic pupils. Decision making by the first aider appeared quite difficult, with children having to wait before

they could have their medication to allow them to get better on their own. They were unsure how they communicated with parents/ carers concerning children's asthma and were uncertain how this could be achieved. This school did not appear to be supportive and take positive actions in its management of pupil asthma.

Children in school seven appeared to be positive in their attitude and management of asthma in school. They liked the fact that they had easy access to their medication, that they could access it when needed and that the school allowed them time to sit quietly, even providing a nice outdoor space to do so.

In contrast, children in school two did not concur regarding where their medication was kept, often spiking debate amongst the children and uncertainty upon this point. They did not feel that they could get their medication whenever required and actively sought other methods to get their medication, borrowing friend's inhalers or keeping theirs with them secretly. Furthermore, these children discuss how they manage their asthma when it gets bad in school, finding reasons to sit down and rest rather than stating that it is because of their asthma that they wish to sit down.

In conclusion, both schools had children who perceived that they were experiencing broadly similar asthma symptoms and limitations upon their QoL as indicated by PAQLQ(S) scores. The majority of children perceived that they were not asthma symptom free, they were restricted in their participation in activities and did feel that asthma was affecting their emotional well being. This indicates that for these children the goals of asthma management were not being achieved (BTS 2009). The goals are to not have limitations upon activities, to be symptom free and minimal psychological impact upon functioning and well being as a result of asthma.

The ethos of the two schools is different, school seven has staff who appeared positive in their management and approach to asthma. Children in this school knew where their medication was kept and were given permission in the school philosophy to access this when they needed it, that they can also seek other remedies such as a quiet space to sit and this was offered in the school environment. School two had school staff who do not feel confident in their management or knowledge concerning asthma in school. They did not give permission for children to have free access to their medication and in fact do not know where asthma medication was kept within school. Neither did the pupils in this school, who also shared similar confusion regarding medication and where it was in the school or even if they should have it on the premises.

Thus it appeared that both schools had children who perceived they were experiencing limitations in their activities due to asthma. However, school seven had children who felt that the school was supporting and helping them, allowing them to manage their own asthma and allowing them to make decisions regarding taking or the need for medication. School two was less facilitative in its attitude to children managing their own asthma and did not allow children access to their medication. Whether this was disorganization or another reason is not explored. Thus children in this school reported devious strategies that they had adopted to manage their disease and discussed quite complex coping strategies that they had developed.

Comparing these schools from differing socioeconomic backgrounds, and other factors as discussed in section 8.2 indicates that in view of the above points it is not perhaps socioeconomic factors directly that are important but rather the themes discussed above. However, it could be that these differences in themes are as a result of the socioeconomic factors that influence how both schools operate. The similar QoL

pattern that children in both schools perceived regarding their asthma would indicate that the children in both schools have similar asthma severities. However, this can only be suggested to be the case since it was not possible to correlating this with GP records to confirm asthma severity and treatment. Or to use physiological measurements of respiratory function which would give precise measures of lung function on the day of data collection.

This chapter has thus illustrated how these results may be synthesized, presenting a picture of what it was like in two schools from the position of staff and children to manage their asthma. The final chapter will discuss the results as a whole and reference them more fully to the literature available, discussing the whole context of this thesis and how this research generates new knowledge in this field.

9: Discussion and conclusion.

9:1 Chapter outline.

This chapter builds upon the literature review and the data presented in chapters four – eight. Discussion illustrates how this research data has addressed both the research questions and the overall research aim. Reference is made to the literature review and the original contribution that this research makes to the literature is demonstrated. The order of discussion of the research questions is clearly identified, this order was considered to facilitate consideration of the key issues and present a cohesive view of the experiences of school staff and children in the management of asthma in school.

Attention is given to the limitations of this thesis and suggestions given for alternative strategies or methodological approaches that could have been used. Evidence is given relating to the research aims and methods used for data collection and analysis, this is critically evaluated. Additionally, possible future directions for further research are expressed. This chapter concludes with overall remarks demonstrating how the author's knowledge has developed in the duration of this research and suggestions for how this research may be used to develop an alternative paediatric asthma associated quality of life assessment tool.

9.2 Discussion of research questions two and three.

2) What policies do schools have in place concerning the management of child asthma?

3) How do these policies compare with National Asthma Guidelines?

Referring to the data presented in chapter five (section 5:3), 82 (70%) of Bristol primary schools replied to the postal survey asking for a copy of their school asthma policy (or related documentation). Only 3 (3.7 % of total Bristol primary school population) enclosed a copy of their asthma policy, the remaining 79 schools (67%) stated that they did not have a school asthma (or related chronic health, medication management) policy. 38 schools (32% of Bristol Primary schools) in their reply indicated that they did not have a school asthma policy but would now write one, having had the absence of a school specific policy brought to their attention as a consequence of the research survey. The overall response rate to the postal survey was very high, at 70%. Postal surveys usually receive a lower response rate (Edwards *et al.* 2002), and in this research a 70% response rate is higher than was expected from reviewing the literature associated with average postal survey response rates. It can be stated that in this local education authority (LEA) a postal survey indicated that the majority of primary schools did not follow DSCF (2007) guidance and have in place a school specific asthma policy. This has not been quantified formally in any English local education authority relating to either primary schools or secondary schools to date.

Reviewing the three returned school asthma policies (see Table 3), found that two of the policies were inadequate compared against the

suggested content for school asthma policies from the DSCF (2007), Asthma UK and BTS/SIGN 2009 asthma guidelines. The third asthma policy was comprehensive in its content and fulfilled many of the requirements from the DSCF and Asthma UK. However, this asthma policy was not implemented within the school at the time of data collection due to operational logistic issues as documented upon the returned school asthma policy.

The DfE guidance states that it is the responsibility of employers (local education authorities) to provide guidance adapted for their schools regarding the management of childhood asthma in school (DSCF 2007). It is expected that this guidance will outline how children with asthma are cared for in school; access to medication; participation in school activities and specific detail/ individual requirements relating to each child with asthma should be recorded within the school. Furthermore, school staff should be aware of the common treatments for the management of asthma and the school should have staff available that can help in the daily management of asthma in the school context. This however, is suggested guidance and not a legislative directive, this is an important differentiation since legislative directives are implemented within school, for example, all school personnel with access to children *must* have undergone an enhanced CRB check is legislation and thus all schools *have to comply*. Whereas it is *suggested guidance* for schools to have chronic health management policies and thus schools have a choice whether or not to comply (but following suggested guidance can and does increase the school's overall achievement in OFSTED inspections).

Judging whether or not school asthma policies are helpful in the management of pupil asthma the literature suggests that specific asthma policies might be useful. The existence of school asthma policies has been advocated in Australia, Canada (McGhan *et al.* 2002)

and the USA (NASBE 2005).. Within the USA there are some states where legislation exists to ensure that the school asthma policies are followed, for example Alabama and New York (New York state 2008). For these asthma school policy legislated states in the US, it appears to have allowed schools to engage with and develop their asthma policies and implement practice that allows school staff and children to manage their asthma positively. This has resulted in children with asthma having less days absent from school and engaging more with school associated activities (Mannino *et al.* 2002).

The results presented in this thesis in association with the research postal survey concerning the existence of school asthma policies conducted within Bristol primary schools is surprising. It was expected that the availability of the guidance from the DSCF (2005, 2007) regarding the management of asthma (and other chronic health diseases such as diabetes and epilepsy in schools) would have been followed. Furthermore, organizations such as Asthma UK provide free resources that significantly help with the construction of school asthma policies and are referenced as a suitable source for additional guidance upon the now DfE website. This guidance together with the aims of the BTS/SIGN asthma guidelines (2009, 2008, 2007) focus upon empowering children to manage their own asthma, minimize and reduce any symptoms associated with asthma and allow children to fully participate in their daily (school) life. These factors were expected by the author to provide enough impetus for Bristol primary schools to have an individual school asthma policy at the time of the research data collection. This is also supported by the growing cohesion (linking together) of practice between schools and primary health care and DSCF and now DfE guidance (DfE 2010).

At the time of research data collection (2008) only three schools possessing an asthma policy was surprising. In 2010 reviewing

Bristol's local education authority's generic web site and the 113 (note lower number than in 2008, since some schools had subsequently closed or merged) school specific world wide web based information (May 8th 2010) suggested that from this source of information the situation had not altered. Many Bristol primary schools still appeared not to have a school specific asthma policy. This was not the expected result considering the increasing pressures placed upon English schools to have a school specific asthma policy.

Qualitative findings gained from interviewing school staff, asking "do you know if your school has an asthma policy?" provided the following summarised information: that some staff thought that their school did have an asthma policy, but could not locate this policy within the school or discuss any items that it might contain. Exploring this further led to staff discussing how they individually managed asthma in school, and related what they thought they should do about asthma and its management, rather than being able to refer to the school asthma policy. Since whilst they thought the school had an asthma policy, not being able to locate it or summarise its contents indicated that their assumption that it existed may have been incorrect. Discussing this informal policy or accepted practice is more difficult to confirm than the postal survey designed to explore the existence of formal school asthma policies. But it would appear from the findings in the qualitative sections of this research, that the informal practice discussed by school staff did not have within it the characteristics of good asthma management and practice as suggested by the DSCF (2007).

This data indicates that primary schools in Bristol LEA are not working cohesively with partner organisations as suggested by the DSCF(2007) policy document 'Every Child Matters' and DSCF guidance for the management of chronic ill health in school (2004, 2007), to provide suitable adequate written guidance for the management of childhood

asthma. The three schools that did have a written asthma policy provided information and guidance of varying quality, with only one of the three schools possessing a policy of adequate content to fulfil the suggested DSCF(2007) guidance. One of these policies was merely a sentence in length, and whilst this attempted to capture a sense of understanding and tolerance towards children with asthma in the school it did not address any of the key tenets of the suggested minimum requirement for a school asthma policy (Asthma UK 2008).

Thus having a school policy alone does not necessarily indicate the quality of the school policy or whether or not it was implemented within the school. School C had a high quality asthma policy (see Table 2) as measured against suggested guidance, but this policy had not been implemented in the school due to logistical issues (a change in headship and governing body resigning) were cited as occurring recently within the school. This then resulted in effectively rendering it useless at the time of data collection.

My literature review (chapter 2) indicates that it is important that schools have and also use a school specific asthma policy. Data in this thesis indicates that for the majority of primary schools in Bristol did not have an asthma management policy. Consequently it is likely that for those children with asthma in these schools, their participation and involvement with school based activities, maximising their attendance at school and social interactions will be reduced as discussed in section 2.6.

It could be interpreted that the lack of school asthma policies in Bristol Primary schools might imply that perhaps these schools do not perceive the management of pupil asthma to be a particular concern. At a time when school personnel are responding to ever increasing pressures of school curricula, performance indicators and requirements relating funding to school academic achievement (MacBeath and Galton 2008) it

might be that school head teachers and governing bodies are focussing upon these issues. However, the health and safety of their pupils should be a primary concern (DfE 2010) and omission of an effective and implemented policy addressing the most common chronic disease of childhood (asthma) (ISAAC 1998, NAC 2004, DSFC 2007) is questionable.

9.3 Discussion of research question five.

What are the experiences of teachers and school support workers concerning their involvement with child asthma management?

Throughout all staff interviews it is clear that school staff feel vulnerable in their management of pupil asthma in school. This underlying feeling is demonstrated when school staff add caveats to their responses which devolve their decision making to the 'best that they can do in the situation', or 'not knowing any more'; or statements which focus upon the fact that they do not know who and where to get support and advice so just get on as best they can.

This position of vulnerability is acknowledged quite formally in the interview with a head teacher who stated openly how she/he would make decisions to enable children with asthma maintain their well being in school, but would not expect her staff to place themselves in such a vulnerable position. Similarly two school first aiders from differing schools discuss how they manage pupil asthma. One is quite forceful in his decision making and acknowledges that he would not have the support from his school for his decisions regarding pupil asthma management. The other first aider did not know what decisions to make and how to best manage pupil asthma, so consequently did not make

decisions since she felt that any decision she made would be wrong within the constraints of her school.

All school staff state that having a formal school asthma policy would help them in their management of pupil asthma within school. In a litigious society having a clear policy with identified points at which further action was required was the most commonly referred to item in all interviews. One school teacher discussed how in her school although they had open access for the children to get their medication, she felt that the school needed a clearly written policy addressing in detail asthma management since in the past she had to defend actions to an angry parent and could foresee this becoming an educational hearing regarding pupil asthma management in school.

Following on from this statement the same school teacher discusses that in her school the head teacher has a positive attitude towards the management of asthma. The children are allowed free access to their medication, the school staff are encouraged to allow children to sit down and rest and they (the staff) have had some education and training about asthma and its management. This school teacher and also the school support worker discuss their decision making with some concern and caveats relating to this, feeling that often the decisions that they made were based upon experiences that they had had regarding pupil asthma and that these had helped in the past and they would try them again. Experiential learning is a positive method to reaffirm learning from practical experiences but can endorse both positive and negative experiences equally. It could be that poor experiences and decision making are endorsed more strongly than appropriate decision making in respect to pupil asthma management.

The DfE places the Local Education Authority (LEA) as responsible for the generation of school specific asthma policies (DCSF 2007). The importance of this role and obligation is highlighted within this research

by the school staff interviews, further substantiated by school staff citing that where policies clearly exist they feel less vulnerable. For example school staff stated that they feel more comfortable and less vulnerable taking children out on school trips since in this situation there is a clearly identified generic local education policy regarding the management of child asthma. This they feel gives them confidence and a position of security that endorses their actions. It is not acceptable to put people in a situation where they feel that their decision making is not based upon full information, with clear support available from the school governing body and senior management. Maintaining the health and well being of school employees is a statutory legal obligation placed upon the local education authorities (DfE 2010), and devolved to the head teacher and governing bodies in practice. School staff find that their own well being is reduced when making decisions and educating children with asthma. This reduction is to such a level that decision making for some becomes almost impossible and this has immediate consequences for the child with asthma who either seeks to make their own decisions in this context, or relies upon friends to help. Neither action is reasonable for a poorly child under the age of 12 to make without the acknowledgement and support of the school when in the school's care. It is important that school staff are supported in undertaking their role within the LEA, and with respect to helping children manage their asthma removing stressors associated by the staff and facilitating decision making by providing school guidance would be helpful. Strategies that school staff adopt to reduce their vulnerability in managing asthma in school included disbelief of children: they decided not to believe what the children were saying, or the symptoms that they were displaying relating to asthma. It appeared that disbelief then negated any action being required of the school staff member. Consequently a poorly child when asking for their medication [salbutamol inhaler] would frequently be told to wait, or that they didn't really need it, or to be ignored by the school

staff member. Children tended to improve, or to become better over the break time [children often took medication in play time discussed in chapter six] and this reinforced the school staff's actions of disbelieving the child. This attitude was articulated by school first aiders and experienced teaching staff alike.

Those school staff that had witnessed a child becoming acutely unwell with their asthma still held a similar attitude and said that they didn't want to do anything since usually it got better and that often children were just putting it on to get attention. This might be due in part to the unequal power relationships between children and school staff and the accepted culture of the school (Barnes 2006). However, there is evidence that children over the age of four can accurately recognise their symptoms associated with asthma and identify when they require their medication (Yoos *et al.* 2003). Disbelieving a child then allows the school staff member to do nothing further, and it can always be said that the child was not bad with their asthma in school or had not told them anything about it, as examined in the Coroner's inquiry into the death of Sam Linton (section 2:5i). This then effectively removes the need to have acted and intervene by the school staff member.,

It is disconcerting as both a health care professional and a human being that an individual's experiences and requests for help are not always recognized by school staff. Certainly, in some cases a delay in seeking and gaining intervention in asthma can cause fatalities (see section 2.5i). The death of this child although reported by the Coroner in January 2010, occurred before the data collection of this thesis and there was an immediate inquiry into the circumstances surrounding his death held by the local education authority. This was cascaded throughout the English local education authorities at the time, and it would have seemed likely that this tragedy should have influenced asthma care in the schools participating in this research. However,

there was no evidence of this apparent in the research interviews conducted and no reference made by anyone regarding this tragic event.

Reducing the feeling of vulnerability can be undertaken by giving school staff information and education that helps them understand more about asthma and its management. Many school staff asked for further information and expressed concern that they did not know enough about asthma and its management and would like to know more; they asked specific questions in the research interviews about how anti-asthma medication worked, what caused asthma, how to reduce the effects of asthma upon the child. Clearly indicated in the interviews by the teachers and support staff that although they felt vulnerable in their decision making and did not always believe the children, they did want to give the child with asthma better care than they had been able to offer in the past. This would be achieved by addressing the areas of deficit that they felt would improve their practice for children with asthma in the future.

This disparity between observed practice and intention to practice by teachers has been commented upon once in the literature. Segal (1998) noted that there was often a mismatch between a teacher's explicit beliefs about teaching and the practices that they engage in the classroom (for example raising voice to admonish children, speaking dismissively to children). Segal (1998) suggested that this was likely to be due to the way that the ideals of 'good teaching' became disengaged in the classroom when faced with the tensions and stressors of everyday practice. Although this is not a recent paper and comments upon the observations gained upon the observed teaching of others in the classroom, it may help explain some of the noted dichotomy discussed in this research. School staff did not enable children with asthma to manage their disease, and actually created difficulties both

logistical and emotional for children to resolve in order to manage their asthma but many school staff reflected that in their interviews they do not know enough about asthma and would like to know more in order to help children. Perhaps in this case, there is a difference between the ideal aims of asthma management and the practical reality associated with the growing stressors of modern teaching (MacBeath and Galton 2008) and increasing tensions of managing and teaching in the classroom (Segal 1998).

School support workers often adopted an approach of managing asthma that involved practical solutions, this range of practical solutions they wanted to understand more fully in respect to how they worked for the child with asthma. Their observation that they were helpful was enough for them to continue to do or participate in the action, for example allowing the children at lunch time play time to sit down and recover; bringing the children's medication out into the playground to facilitate children's access to their inhalers; encouraging children to stay away from flowers and pollen that made them wheezy. However, when discussing their actions they often added that the school did not know that they did that, or the head teacher would not be happy with their actions. It seems incredulous that a school head teacher would not endorse actions that helped children with asthma to enjoy their lunchtime play sessions. The actions of school support staff surely would be supported by a reasonable head teacher. This questions whether school support staff feel that their contribution to the running of the school is not valued by the head teacher, or that they value themselves so lowly in the school hierarchy that they cannot comprehend that their contribution is appreciated by the head teacher.

School first aiders should be in a position to manage children's asthma in school, as the most common chronic disease in childhood it is taught on all school first aider programmes (DfE 2009). However, the three

school first aiders that were interviewed in this research from differing schools had a diverse range of knowledge and understanding about asthma and its management. One first aider who knew a significant amount had acquired his knowledge outside the school first aider role, this knowledge he brought to the school and used in his school role. However, he stated that the training the school first aider course had given him was not adequate for his role. Another first aider replied that she had not had any training in the management of asthma and found that making asthma related decisions was beyond her, consequently the children with asthma in her school the head teacher made sure were seen by another member of staff who herself had asthma.

School staff discuss that they do not know how to recognise when a child has need for their medication, or when they are becoming acutely unwell and required further intervention. School staff accept the role of *in loci parentis*, for all children attending their school. Reasonable parents are expected to assess children's well being and health, provide access to medication, recognise when their child's asthma is deteriorating and reduce from the environment factors that they know cause their child's asthma to become bothersome. Many school staff do not cite experiences and actions that resemble those of reasonable parents.

Following upon this reasonable parent responsibility that school staff assume is the common theme related to communication between school staff and with the parents/carers of school children. Many school staff felt that communicating with colleagues and parents/carers of children was generally ineffective regarding asthma and pupil management and care. Discussing incidences and experiences where communication had not occurred reliably and resulted in increasing their insecurities and vulnerability around asthma management of school pupils. The DCSF (2007) stressed that effective communication between school personnel

and outside agencies and parents/carers of children was crucial to improve children's well being and facilitate their development into adulthood.

9.3i Summary of the school staff experiences and additional information that this research thesis adds to the established literature to date.

Many of these experiences and discussions were not expected to be the findings of this research. Reviewing the literature indicated that school staff were often unaware of the signs and symptoms of asthma (Szcepaniski, Brockmann and Friede 2001, Gawwad and El-Herishi 2007) and indeed this was substantiated in this thesis. The literature indicated that the situation was slightly better when considering secondary school teachers and in particular those that had physical education teaching focus, but there was no literature available to establish what primary school staff knew and understood about asthma and its management. In the absence of any literature it seemed reasonable to expect designated first aiders to have a better working knowledge of asthma and its management but this was found not to be the case.

To date no interview based research has been conducted within the UK with primary school staff to explore their experiences of managing asthma in school. The inclusion of school support staff was made to recognize the growing role and responsibility that these staff have in providing a safe and secure school environment. The findings of this thesis suggest that six Bristol primary schools are not supporting their staff in the management of pupil asthma, school staff are finding that generally they are very vulnerable in their roles and decision making regarding asthma management in school. Many school staff have inadequate knowledge regarding the management of asthma as defined

by the standard of reasonable parent and the BTS/SIGN (2008) guidelines. Some key staff admit that they avoid making decisions by disbelieving children and not engaging that the child requires help with their asthma.

These experiences and findings from both school teachers and school support workers in Bristol Primary schools significantly adds to the literature which has to date not explored the experiences of school staff managing asthma in primary schools. The literature to date does not acknowledge that school support staff have a role to play in the management of pupil asthma, this research addresses the role that school support staff play in supporting children in school. The qualitative approach of using interviews that were not prescriptive in their design has allowed thoughts, experiences and feelings to be discussed that would not be established using a questionnaire approach (for example the questionnaire used by Hussey 1999). This adds validity to the themes discussed in chapter four and extrapolated further in this discussion, since the topics and ideas were generated by the staff research participants and not pre set in a prescriptive methodology required by a questionnaire approach.

These observations and findings resulted in a return to the literature to search for examples of situations in which staff were feeling vulnerable /insecure and related feelings, this found no research articles from any of the relevant databases or similarly using grey literature sources. This was not an area or search strategy that was implemented in the initial review of the literature and not suggested from considering the wealth of literature read and synthesized in the duration of this thesis.

Consequently these findings are exquisitely adding to the body of knowledge regarding asthma and its management in school as well as the experiences of school staff in their management of chronic pupil health conditions.

The results are both surprising and disturbing and indicate that managing asthma in school for school staff is at its best satisfactory, and for many school staff an additional stressor and cause of feelings of distress and inadequacy.

9.4 Discussion of research question one.

What are children's experiences of asthma within primary schooling?

Overall children in all the seven Bristol primary schools considered in chapter six and seven that having asthma and managing it in school, was at the least annoying to them and for many children a significant detriment to their schooling and well being. There were two distinct aspects of having and managing asthma that the children commented upon frequently: the first was coping with the symptoms of asthma in school and the physical consequences that these had; and the second was the emotional and psychological effects of having asthma upon their relationships, participation and interactions with others within school.

The symptoms of having asthma that children found difficult to manage were particularly focussed upon feeling breathless, coughing and wheezing in school, excessive mucus production and reduction in physical exercise tolerance. That these children had such symptoms indicates that their asthma was not managed as required by the aims of the BTS/SIGN (2008) asthma management guidelines, these guidelines are quite clear that children with asthma should not have any symptoms of asthma that limit their physical activity. The presence of such symptoms indicates that these children were not in receipt of anti asthma treatment that was adequate to maximise physical functioning and well being.

These symptoms the children sought to manage by adopting various sophisticated coping mechanisms and strategies. For many children the symptoms of asthma were such that they actively reduced their participation in exercise and physical activity. Van Gent *et al.* (2008) suggested that children with asthma frequently do not participate in sport activities, similarly Rabe *et al.* (2000) report that 78% of children state that the worse thing about their asthma is their inability to participate in sport based events. Findings presented in this thesis indicate that children did report not participating fully in physical education based activities, either by complete non participation, or by reducing their commitment and effort to the sporting task so that it would not induce their asthma symptoms. For example, running slower than they were able so that they would not become wheezy, reducing the amount of time that they ran to kick the football, being one of the last in the school race.

However, these reductions in physical activity were not limited to identified teacher led physical sporting tasks within the school. They also considered reducing the amount of physical activity that they did during the school day. Some children (n= 48) discussed how they planned the route from one classroom to another, to allow them maximum time and rest opportunities so that they did not have to cope with wheezing and feeling breathless. Similarly others (n= 63) discuss how they found their asthma was triggered when walking up and down stairs or walking around the school grounds at lunch time.

Consequently these children (n= 111) reduced their participation in these activities. This perception of the effects of asthma upon the children's level of activity is also sustained by the results from the PAQLQ(S). All 137 children reported in their perception that asthma limited their activities, 40% of these children indicated that 'most of the time' they had to reduce their activities because of their asthma. This is

unexpected results and indicates that children are experiencing a high level of symptoms and associated morbidity above that suggested in the literature to date. Also that for whatever reason their current level of received treatment is not adequate as measured by the aims of 'best practice' (BTS/SIGN 2008).

There are known physiological consequences associated with a reduction in physical exercise, such as decreased cardiac output, hypertension, increased risk of cardiac disease, obesity, lowered circulating adrenocorticoids and increased risk of diabetes (Greenleaf 1982, Mokdad 2003, BTS/SIGN 2009, Hardman and Stensel 2009). All of these significantly increase the risk of long term poor health and chronic illness in adulthood, and are expected to cost the health service in excess of £3.6 billion in 2010 (House of Commons 2002) . The aim of recent guidelines and initiatives have been to increase physical activity in childhood and promote healthy living, to reduce the known sequelae of physical inactivity in the population (Government initiatives such as 'fit for life', 'everyone active', 'healthy eating' – further information available from direct.gov.uk (online) (2010), DSCF 2007). However, without adequate asthma symptom management children with asthma are not only reducing their taught sessions of physical activity but also their informal (play associated) physical activity and thus increasing their risks of long term health problems.

Some of the known sequelae of physical inactivity such as obesity, diabetes and lowered levels of adrenocorticoid hormones in themselves can exacerbate the management and treatment of asthma (BTS/SIGN 2009, Sutherland 2008). Consequently maximising physical activity is a key priority within the BTS/SIGN asthma guidelines (2009). It is expected that children can manage their asthma symptoms by reducing their trigger factors as stated within the BTS/SIGN 2008, 2009 and GINA 2004 guidelines. However, in this situation the self management

strategy adopted by the children confounds the sequelae of factors that also follow from chronic ill health and inactivity. These 'mal adaptive' coping mechanisms can thus increase the long term physiological consequences of the disease that they are seeking to manage in the short term.

It could thus be possible that children with asthma leave primary schools with additional chronic health problems as a result of inadequate asthma treatment in childhood. In this thesis the level of asthma symptoms that the children were experiencing significantly reduced their ability to participate in school activities, and as discussed this potentially increases their risks of developing other diseases.

The emotional and psychological effects of having asthma upon their relationships, participation and interactions with others within school resulted in children choosing their friends very carefully (see chapter six). The PAQLQ(S) sub domain perceived emotional effects of asthma, indicated that all children in this research perceived that their asthma affected this component of their life. Children perceived that the effects of asthma had the greatest impact upon their emotional associated quality of life, this sub domain received the lowest score in this research and had over 40% of the children considering that they were 'quite bothered' by the emotional effects of asthma upon their quality of life (see 7:6.2). Children described how they felt different from their friends and peers who do not have asthma, explaining that other children stared at them when they took their medication or become wheezy and coughed and spluttered. Some children stated that they lost friends when it became known that they had asthma, or that they only chose friends who also have asthma since they understood what it is like to have the disease. Reduced friendship groups and feelings of isolation were commonly reported in this research.

Celano and Geller (1993) describe how social isolation and well being influences children with asthma and also the children's families. Even mild asthma can result in children feeling socially isolated (Usherwood *et al.* 1990, Townsend *et al.* 1991, Nocon 1991, Christie *et al.* 1993, Gentile 2008). The children in all seven schools within this research all discussed feeling different and stated that they were not fully included in friendship groups in their school, this clearly affected their emotional well being. Bee (2009) discusses how emotional well being is considered to be a key component for reducing stressors associated with development into adulthood. Furthermore, good emotional well being is associated with developing resilience and reduce the known consequences and risks associated with chronic ill health predisposing to developing mental ill health (Cadman *et al.* 1986, Newacheck and Taylor 1992).

It seems that the children in this research were aware that their asthma influenced their interactions and inclusion into friendship groups within the school, they felt different and tried to develop friendships and coping strategies that helped reduce this difference but this did not allow full inclusion into school life. Feeling socially excluded is a clear risk factor for developing mental ill health, and it challenges children's emotional well being.

Choosing friends and being included was a very important issue that children discussed. However, they also discussed how they chose which member of staff to approach for help if they needed with their asthma and why. Indicating in their discussions quite sophisticated factors that they had assessed and evaluated in their consideration of which member of staff to approach and why. Children describe characteristics of staff that they feel they can approach and ask for help, these characteristics include understanding what asthma is, allowing children to get their medications and most importantly believing the

child. Children are quite clear that they feel some teachers believe them and some do not. This assessment and decision making that children had regarding which member of staff they would be able to ask provided quite a challenge to their emotional well being.

Considering the known power dynamics within schools around relationships between school pupils and school staff, children knew that there were some staff that were more accessible than others. When children had asked the 'wrong person' concerning their asthma and needing help often the children were rebuked, shouted at and left to manage their asthma themselves, this is despite the fact that the child had asked for help because they could not manage their asthma. Children discussed how this made them feel, and stated that it made them sad and worried in case they had to ask that person again. Clearly challenging their understanding of what they thought school staff were able to do and the care they could provide. Adding to the factors that reduced children's emotional well being and resilience and causing anxiety. Butz and Alexander (1993) state that anxiety in children who have had an asthma attack and fear of another one is a significant contributing factor in subsequent attacks, BTS/SIGN (2009) guidelines further substantiate that anxiety can produce and exacerbate an asthma attack.

Increasing children's anxiety and reducing their mental and emotional wellbeing are significant unintentional factors resulting from children's experiences of asthma management in school. Confounding these experiences children discuss how they adopt subterfuge to help in the management of their asthma, stating when they use these coping mechanisms they know that it is wrong and they should not lie or be deceitful but it is the only way that they can cope with their asthma. Such methods of coping include secretly keeping their asthma inhaler with them in their possession and using it when needed (and when no

one is around) since the school did not allow children to have their inhalers with them; pretending that they need a drink of water so that they can sit down and get their breath back; tying up and re-tying shoelaces so that they can stop and rest. Children say that they lie so that they do not get shouted at and can get their breath back by doing other things. Adopting deceitfulness and subterfuge caused the children in their discussions to consider whether or not this was acceptable and justify it generally by saying that it was better to lie than to be shouted at or laughed at. It could be considered that this level of decision making challenges children's emotional well being.

A very small group of children from one school (school seven) did have slightly different experiences managing their asthma in school. This school did allow children to access their medication freely and allow children to rest when required. However, children from this school still found the emotional consequences of having asthma to be as bothersome to them as those in other schools. Children from school seven discussed choosing which member of staff for help with similar conditions as expressed by other children, and similarly found the effects of social isolation to be problematic to their participation in school life.

9.4i Summary of the school children's experiences and additional information that this research thesis adds to the established literature to date.

Children with asthma in schools are facing significant challenges to their emotional well being (integrity), these could potentially lead to poorer emotional adaptation of these children in respect to their emotional integrity and robustness as an adult. Consequently this may increase the risks of developing mental illness in adulthood. Increased anxiety is a significant risk factor for inducing an asthma attack, or exacerbating

asthma and at times children in school feel quite anxious about managing their asthma and the decisions they make. The research literature is limited considering the effects of asthma and emotional stability and well being. This thesis presents a considered argument that this appears to be a significant factor in maintaining the health and well being of children.

Children feel isolated and different from their friends and try to find strategies that allow them to minimise the effects of asthma upon them so that they can reduce this isolation. For some children the physical symptoms of asthma are such that they significantly reduce their physical activity within school. Reducing physical activity increases their risk of developing a number of chronic health conditions in adolescence and adulthood.

The established literature indicated that children with asthma did not participate fully in physical activities and that they did experience some degree of isolation. However, this thesis indicates that children are experiencing a high degree of reduction in physical activities to such an extent that this limits their participation in play time activities and moving around the school grounds and buildings. These limitations and perceived effects upon their quality of life are supported also by the data gathered using the PAQLQ(S).

This thesis presents the argument that in seven primary schools within Bristol children are experiencing significant reductions in their asthma associated quality of life. These children have adapted their participation and involvement with and in school life to allow their attendance at school. However, exploring these strategies it would appear that they have 'mal-adaptive' coping mechanisms that potentially exacerbate their asthma and increase their risk of long term chronic physical and mental health problems. These findings allow the presentation of new challenges to the management of childhood asthma

and adds to the literature and understanding of children's management of asthma in school.

9.5 Discussion of research question four.

Are there differences between schools concerning their asthma management?

For the seven schools considered in this thesis the following section presents a summary of their pupil asthma management. One school did have an asthma policy which allowed children and school staff to be more assured in their management of childhood asthma. These assurances resulted in children feeling that they could access their medication relatively easily, that they could rest when becoming wheezy and were assured of times to be quiet when their breathing became bothersome. The remaining six schools did not have a school asthma policy, did not enable children to access their medication or rest when their asthma was problematic. Their staff generally felt less assured about their pupil asthma management, and were concerned that they were making poor decisions, or no decisions at all.

Children experienced limitations to their perceived quality of life and these limitations are broadly evaluated similarly across all seven schools. Socioeconomic factors related to the geographical area that the school is located in did influence children's perceptions slightly as quantified by the PAQLQ(S) see section 7:5.1-7:5.2. For example children in schools two, three and one (lowest socioeconomic grouping) indicated that their asthma reduced their physical activities slightly more than children in school seven. However, considering the overall PAQLQ(S) score for each child and the range of scores within each school indicated little variation. This could be explained by the observation that those people in greatest need of health care and

intervention often do not assess their situation as requiring such intervention. This is an example of the inverse care law (Hart 1971); which states that the availability of good medical care tends to vary inversely with the medical need for it. Thus it is possible that those situated in socioeconomic affluent areas receive good quality health care and increase their expectations, whereas those in areas of lower socioeconomic areas often have access to poorer services and have lower expectations about what their health care should or could be. Consequently in the context of this research it could be possible that the children in school seven expected their asthma to be better than it was and thus rated their asthma associated quality of life low. The children in schools of lower socioeconomic areas did not expect, know or consider that their asthma could be better than it was and thus considered that its effects were not as important upon their quality of life.

Reasons for considering this is that the experiences that children discussed in managing their asthma was very similar in six schools. For example feeling different, using alternative strategies to get time to rest and the words and feelings that children used to describe their asthma. Some children in six schools related clinically significant factors that indicated their asthma was not well controlled at that time, such as not being able to walk and talk, or only being able to walk a few steps before needing to use their inhalers. According to the BTS/SIGN guidelines (2008, 2009) this indicates that their asthma was not achieving optimum control at that time. However, the PAQLQ(S) did not indicate that for these children the perceived asthma associated quality of life was not as poor as the experiences the children recited. In school seven located in the highest socioeconomic area, children did not relay experiences of managing asthma which would be ranked as severe according to the BTS/SIGN 2009 guidelines. Nonetheless they did perceive that their asthma affected their quality of life more than children in some of the

lower placed socioeconomic schools. Asthma UK (2007) indicated that access to health care and asthma related management was a significant factor in the known disparity between asthma admissions and mortality. Perhaps the children in schools one to six had differing access and expectations to health care than children in school seven, and further confounding their asthma management and well being.

This research could be extended to evaluate the health care services available and their use by the children participating in the research. Base line respiratory function measurements and access to medical notes for medication prescribed could provide a quantifiable indicator of asthma severity. These measures could help address and answer these issues arising from this research.

Children all have experiences of asthma management in school when things have not gone well for them, they all can talk about feeling different from others and not knowing how to manage their asthma for the best. School staff are not all accessible and supportive and children discuss how they recognize this and work with these facts to ask the right person when they need help.

Schools discussed in this thesis had children with similar experiences of asthma and its emotional affects. A school that had an asthma policy did have vary slightly differing experiences expressed by its children and these children felt slightly less reduced in physical activities by their asthma than other children in the remaining six schools. Similarly school staff in this school did feel that they knew about asthma and could help care for children with asthma in the school day. School staff in the remaining six schools felt more vulnerable in their decision making and care of children with asthma.

9:6 Noteworthy methodological issues.

The choice of PAQLQ(S) is discussed extensively in chapter seven, and the results are presented in chapter seven. Using the PAQLQ(S) and considering the data it generated in this research created the following criticism of this questionnaire and its limitations. The Juniper questionnaire is well validated within the research area of paediatric asthma, it has been accepted as a reasonable and reliable methodological tool for over two decades (American Thoracic Society 2009, British Thoracic Society 2008). The questionnaire has been well established to supply meaningful data by comparison to conventional clinical asthma measures (symptom control, peak flow rates, airway responsiveness, global rating of asthma) and also generic HRQL measures, Juniper *et al.* (1999), Rowe and Oxman (1993). Thus Juniper *et al.* have developed a questionnaire that they believe reliably indicates the perceived effect of asthma upon QoL in children aged seven years and above. The three sub domains of the PAQLQ(S) are: symptoms, activity and emotional affects upon quality of life.

Juniper *et al.* (1999, 2004) present an argument that since asthma associated quality of life and this research questionnaire is not one-dimensional every question has value and should thus be included. (This argument is presented earlier in chapter seven). However, in this research thesis the data obtained provided some statistically significant findings that challenge the claims of Juniper *et al.* regarding their PAQLQ(S). Essentially this thesis challenges the notion that all 23 questions need to be asked. It appears possible from this data set presented that it should be achievable to identify only three core questions which need to be asked, in order to generate a robust Quality of life score for young people. Since completion of this thesis discussions with Elizabeth Juniper support this possibility, based upon the following key points.

Within this data set there was a strong correlation (greater than 0.87) found between each of the three sub domains of the PAQLQ(S). Statistical correlation was applied following consideration of this research data and noting that there appeared from personally hand plotting this data to be a correlation between the three domains. This was discussed in section 7:6.3, from the data presented in section 7:6.3 there is a strong correlation between all the three sub domains. A correlation between sub-domain scores does suggest that a very high level of internal consistency (used in statistical terms not relating to internal consistency of a questionnaire design), or redundancy, exists in the questionnaire. For example Activity PAQLQ and Symptom PAQLQ scores are incredibly statistically similar, thus it is worth considering if it would be possible to avoid the bother of asking both sets of questions.

In view of this powerful correlation between all three PAQLQ(S) sub domains this does not appear to be clinically incongruous with the known association between disease pathology and effects upon physiological functioning. For example, experiencing symptoms of asthma such as breathlessness and wheezing which occur daily would reduce physiological ability to participate in sports and associated activities. Thus there should be a positive and statistical significant correlation between symptoms of asthma and ability to participate in daily physical activities.

The greatest correlation was between the emotional domain of the asthma PAQLQ(S) and comparing it with activities domain and then symptoms domain. This should be expected, since the age range that this questionnaire was given to in this thesis ranged from seven to eleven years. In this age range it is important to participate in activities with peers (Milton *et al.* 2004) and this importance should not be underestimated. Thus any factor which makes one individual different

from another can cause and would be expected to cause emotional affects.

The justification to utilize Juniper *et al.* (1999) PAQLQ(S) questionnaire is presented earlier in chapter seven. However, throughout the analysis of this data methodological problems relating to analysis of this questionnaire have arisen, influenced by the problems arising when the children undertook the completion of the questionnaire, arising because they did not understand aspects of the questionnaire's terminology. These were not foreseen when the decision to utilize Juniper *et al.* PAQLQ(S) was made and will be discussed more fully below.

9:6.1 Comprehension of PAQLQ(S) by children.

Juniper *et al.* (1999, 2004) state that when they piloted and validated their questionnaire children over the age of seven could comprehend and appropriately select their response to the questions. This is demonstrated by selecting a numerical score to signify their response against key words, the children read descriptions and select the number which represents their perception. Juniper *et al.* (2004) describe how they validated their questionnaire. This was as follows, initial validation of the PAQLQ(S) was with a 1000 children who were asked to complete the PAQLQ(S). Their responses were correlated against reported symptoms as perceived by parents/ carers. Whilst this is certainly a large number of children to pilot and validate a questionnaire for initial publication and use of the questionnaire in 1996, subsequent work has related to translation of the questionnaire into many languages rather than focused continued validation of the questionnaire.

Children in this research completing this questionnaire found it very difficult to distinguish between the words and their interpretation. For example, many children asked what was the difference between 'quite bothered' and 'somewhat bothered', and 'bothered a bit'? This was quite a common event during the completion of the PAQLQ(S) and not limited to this example. It was the researcher's impression that children found interpretation of the words used in this questionnaire difficult, often selecting their responses from ones they were more sure of such as 'all the time', or 'none of the time' for example.

It is clear when considering the choice of written responses in the PAQLQ(S) that this is an example of an ordinal scale only. Although the authors and other researchers imply and thus use statistical analysis associated with gaining nominal and interval data that the generation of the PAQLQ(S) overall score from the response selection is in fact an example of categorical interval scale only. For example in the PAQLQ(S) there cannot be applied and assumed to be the same numerical difference between statement numbers 2 and 3 as statements numbered 4 and 5 (regardless of whether the green or blue card is used – see appendix vii).

As previously discussed (section 9.6) within this data set it is possible to identify that three questions from the PAQLQ(S), one from each domain could be used to assess each child's perceived asthma associated quality of life. This was an unexpected result and would suggest that it may be possible to begin to question the merit of using the PAQLQ(S) questionnaire comprising of 23 questions. The choice of using the PAQLQ(S) was made and considered as comparing it against alternative questionnaires (such as French 1996) the PAQLQ(S) was substantially a more robust tool.

It must be acknowledged that this questionnaire (PAQLQ(S)) is used throughout the paediatric asthma literature, is well validated, using

comparison to conventional clinical asthma measures (Rowe and Oxman 1993, Juniper et al. 1993, American Thoracic Society 2010). There is sound research indicating that PAQLQ(S) is reliable and robust, in comparison to generic HRQL measures such as the Rand (Hays and Morales 2001) and SIP Patrick and Doya 1989 offered by Juniper et al. (1992). It is also considered very reliable and suitable for research use (Juniper et al. 1995, Rutten-van Molken et al. 1995, Frazen et al. 1996, Israel et al. 1996, Boulet et al. 1995, Kemp et al. 1998, Turner et al. 1998, Bowling 2009) and this certainly influenced my decision to utilize this questionnaire.

There is potentially life threatening consequences to not making the right decision in asthma management; however these rarely happen (only 40- 50 children die as a consequence of their asthma on average each year in England (ONS 2002). Considering the high symptom level that children in school claimed they had it is surprising that severe consequences of asthma are not more frequent in the school setting. However, this might be due to children demonstrating very effective methods of reducing their asthma symptoms in school by not participating fully. Or that children with obvious respiratory symptoms are granted access to their medication regardless of the 'normal' attitude of the school staff.

School is expected to provide a safe environment for children, seeking to promote positive attitudes towards education and well being. From these research findings it would appear that in the context of coping and experiencing asthma from both children and school staff perspectives this was not the case for the Bristol primary schools that participated in this research.

9:7 So what does this mean in the context of policy?

Considering the policy arising from 2003 'Every Child Matters' as a consequence of the death of Victoria Climbié this programme aims to give all children the support they need to:

“be healthy, stay safe, enjoy and achieve and make a positive contribution to economic well being.” (Introduction paragraph, page 7)

The Every Child Matters agenda has been further developed through publication of the *Children's Plan* in December 2007. The Children's Plan is a ten-year strategy to make England the best place in the world for children and young people to grow up (DCSF 2007).

The Plan aims to improve educational outcomes for children, improve children's health, reduce offending rates among young people and eradicate child poverty by 2020, thereby contributing to the achievement of the five Every Child Matters outcomes (Every child matters: change for children 2004).

Consequently in the context of this research some Bristol primary schools have yet to take significant steps to achieve the ideals set out in the plan 'every child matters' and related publications such as the Tomlinson report (2004). In fact in respect to asthma the schools are failing significantly to reach the key aims of both asthma management guidelines and the aims of 'every child matters'.

9:8 The value of mixed methods in this research context – a consideration at the conclusion of this thesis.

Teddlie and Tashakkori (1998) consider the most important step in any mixed methods study is when the results from both the qualitative and quantitative strands are incorporated into a coherent conceptual framework that provides an effective answer to the research question. For this research it was possible to concentrate upon either qualitative or quantitative data at various stages in the creation of this thesis, however developing an understanding of the whole data and generating a conceptual framework marked a significant milestone in the value of both strands for a cohesive understanding of the phenomenon of managing asthma in primary schools.

Making sense of the findings in both research strands requires understanding of the process of constructing meaning from a relatively large amount of data collected. This then requires inference (comprehension and understanding of how the research data from all the strands of enquiry interrelate) and generates a conclusion made on the basis of obtained results. Inference as both a process and an outcome proceeds as a dynamic and interactive manner throughout the process of research (Teddlie and Tashakkori 2007). Creating an understanding or 'whole' on the basis of all results, this 'Gestalt' is a bigger than a simple set of isolated conclusions made on the basis of different findings of this study.

Making inferences is both an art and a science (Cresswell and Plano-Clark 2007), involving elements of creativity, intuition and meaning making as well as the ability to compartmentalize components or aspects of a phenomenon, understand each and then reconstruct them

for a full understanding. Tashakkori and Teddlie (1998) discussed that a golden rule of making inferences in human research is knowing the participants, accepting this premise allows possessing a solid understanding of the cultures of the participants and the research context to be a valuable asset in the process of making inferences. Furthermore, arguing that even in highly structured quantitative research studies making meaningful inferences on the basis of obtained results will be enhanced by the researcher's knowledge of the respondents. Taking into account how they perceived the research process as well as the meaning of behaviours in the cultural context of the participants.

For this research process the value of mixed methods research methodology is demonstrated throughout this thesis. Without both strands of the approaches used in exploring the experience of school staff and children in respect to asthma in school it would not be possible to present the picture, or overall results presented earlier in this discussion. Using only either qualitative or quantitative approaches would have produced a far less detailed understanding of the experiences of children and school staff in their asthma management. This understanding of the experiences has been increased by the researcher conducting both qualitative and quantitative research, together with a full understanding of the process that the research participants have undergone has increased the conceptualization of the whole phenomenon. This has been suggested by Teddlie and Tashkori (2007) that mixed methods research exploring the same phenomenon can help generate researcher awareness of conceptual and methodological problems experienced by the research subjects, and generate a gestalt view of the phenomenon that would not be possible by one method alone.

Without the use of qualitative methods of enquiry it would not have been possible to explore the experiences of children and school staff in their

understanding and management of asthma in school. Qualitative methods of enquiry allowed the generation of rich data that was not preset or pre ordained, with the use of free narrative approach allowing the participants to describe their experiences freely. Quantitative methods of enquiry allowed the establishment of how many Bristol primary schools had asthma policies, and also quantify the perceived effects of asthma upon children's quality of life. It can thus be answered with reference to figures and numerical values how children perceived the effects of asthma upon their quality of life and also how they perceived the effects of asthma upon their daily functioning and interactions with their peers.

Thus mixing both methods of enquiry has produced the discussion presented throughout this thesis. This thesis is a considered presentation of the experience of managing asthma in school, referring to all the strands of enquiry used and a portrayal of the experiences of school staff and children in 2008. It would not be possible to have this thesis and this gestalt picture without using mixed methods.

9:9 The researcher's development in the understanding and value of mixed methods, a résumé upon its value at the completion of this thesis.

At the commencement of this doctoral programme of study (2007) the researcher's understanding and experience of mixed methods research was that it existed and had in some cases been quite successful. Reviewing the literature concerning mixed methods produced some detailed research papers and a few textbooks, but generally there was limited information regarding the use and construction of mixed methods research. For example Cresswell and Plano Clark, Tashakkori and

Teddlie wrote in the late 1990's and early 2000's concerning mixed methods research methodology.

However, as the research for this thesis has developed with time simultaneously there has been a growing interest and enthusiasm for mixed methods research in the wider world. During the construction of this thesis a significant number of textbooks and journals now exist focusing upon mixed methods research.

The researcher's understanding of mixed methods has increased throughout the last three years, at the same time the academic world has altered and the value of mixed methods enquiry has now been firmly established (Morrison 2009, Gerrish and Lacey 2010). The experience of gathering both qualitative and quantitative data within the same strand of research enquiry has not been without its methodological challenges. However, the quality of data gathered and the whole picture thus presented in this thesis, demonstrates that using mixed methods has allowed a greater understanding of the phenomenon of the experiences of school staff and children managing asthma, than would have been possible using only one approach in isolation.

In conclusion the process of using mixed methods, researching within schools and making inferences surrounding the research findings that represent the differing synergistic strands of enquiry has been challenging. The considered, synthesized and analyzed experience of asthma management within Bristol primary schools has been presented in this thesis. Mixed methods have provided a methodology that has allowed the research questions to be addressed and development of an understanding of the value of differing methodological issues. It has provided challenges and has resulted in the researcher developing in experience and understanding of this methodological approach.

9:10 Conclusion, criticisms of this research design and directions for subsequent research.

Finally, the overall school environment has many challenges for both school staff and school children managing asthma; it is for many a difficult route that they tread. This thesis presents a considered examination of the experiences of school staff and children in the management of asthma in seven Bristol primary schools. It has provided evidence that there were commonalities and the phenomenon of pupil asthma management presented significant challenges to children and school staff during the school day. School staff felt vulnerable in their management of pupil asthma, and reduced their vulnerability by adopting coping strategies that could be detrimental to childhood asthma management. Similarly school pupils with asthma reported that they felt disempowered in their own asthma management, and resorted to subterfuge and disengaging from school activities in order to manage their disease as best as possible in the school day. Communication between school staff, school pupils and their parents/carers was at times difficult and it appeared that collaborative working with outside agencies in order to address and develop children “to be healthy, stay safe” (Every Child Matters 2003 page six), did not occur as aimed for by the government of the day.

Using mixed methods as a methodology has resulted in the development of the researcher and a deeper understanding of the use and value of qualitative methods of enquiry. Researching with children and school staff was both a source of personal growth in this area and a privilege that provided insight and rewards beyond my initial premises at the conception of this research enquiry. It has been a challenging

environment to research within but very worthwhile. This was a very large research study, which was complex and required a significant amount of time for a sole researcher to undertake. Each individual research question (from the five listed) presented in chapter two and three would have been sufficient to explore in detail without the combined effects of addressing the related aspects posed from the other four questions identified. A more focused approach would have resulted in more extensive discussion, which would have identified sufficient new and relevant information. Designing a mixed methods research approach does not require lots of questions, rather an emphasis upon the phenomena (see Figures 1 and 2), and I would argue for a flexible, adaptable and responsive conceptual framework that allows exploration of the phenomena. For example within this research, it was discussed at the point of data collection why was it only three schools had asthma policies? It would have been interesting to explore this point and find out more about this, however, the drivers and approach already set for this research did not allow this to be pursued. I would suggest that a responsive framework would allow exploration of issues of interest as they develop. This would allow a research design that would truly benefit from the possibilities of mixed method research to be responsive to the phenomena being explored.

The use of the PAQLQ(S) and the methodological problems presented in this thesis has led the researcher to consider if it would be possible to develop another assessment tool that would not contain these inherent problems. Critically considering all the research findings gathered in the data collection phase of this research (as discussed in this thesis only seven school's results are presented, but more research data was gathered) has led the researcher to consider that the development of

another paediatric asthma associated quality of life assessment tool would be an outcome from this research.

Furthermore, the perceived affects of asthma upon children's HRQoL were higher than expected and the next research steps also involve correlating asthma severity as confirmed by diagnosis and assessment of child's physiological respiratory functioning against reduction in activities. This would then allow greater exploration of how asthma severity (as defined by the BTS/SIGN 2009 guidelines) is perceived to affect children's HRQoL. Firmly correlating each child's respiratory physiological parameters, such as peak expiratory flow rate with their perceived quality of life was considered at the initial stage of research design, however the ethical design issues associated with gaining permission to assess document and record formally asthma associated physical parameters was acknowledged as too big for this research design. Future research should focus upon working with far fewer research subjects and ensure that recording physiological respiratory function was undertaken. Acknowledging that this would mean that correspondence between the child and their families primary care providers would have to occur if physiological measurements indicated that the child's asthma was unsatisfactorily managed, it would be no more burdensome to develop than the requirement to develop a policy adequately safeguarding vulnerable subjects. Fewer research subjects together with fewer schools purposefully chosen to represent some of the key variables associated with schooling would allow this to be possible.

Asthma remains the most common chronic disease of childhood, within Bristol evidence has become available to indicate that the average age of hospital admission for an asthma exacerbation is ten years of age, in comparison with the average age (in England) of asthma associated hospital admission as 24 years old (University Hospitals Bristol NHS

Foundation Trusts Trust 12th December 2010, audit of asthma admissions personal communication). This thesis will allow dissemination of these research findings and begin to influence asthma management in primary schools in the future and perhaps help identify some of the inequalities that influence the asthma admissions within Bristol. Chapters six and four of this thesis have been presented at request of the DH as supporting evidence around the issues asthma can cause in schools. These were presented to the commissioning board and review panels jointly comprised of members from both the DH and DE in 2013 which were meeting to generate the following guidance : “Guidance on the emergency use of salbutamol in schools” HM Government (2013) available from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/360585/guidance_on_use_of_emergency_inhalers_in_schools_October_2014.pdf [Accessed 14th October 2014].

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Appendix i: search strategies used in development of the literature review, an overview.

Developing a search strategy for the commencement of this research involved considering the research topic, research questions and location in detail. Evidence considered in the generation of the literature review came from many sources, these included books, journals, reports, conference proceedings, theses, government reports and command papers and also grey literature. Searching these sources required systematic strategies which are summarized below.

Identification of many sources of information used in this literature review originated in electronic searches, this included electronic searches of library book holdings, electronic data base searches, Cochrane reviews and using electronic searches via the world wide web. However, the researcher had a good working knowledge of the research area at the commencement of the research and this familiarity helped with the development of key research terms used.

Using both PICO (People, Interventions, Comparisons and Outcomes (Booth and Fry-Smith 2004)) and SPICE (Setting, Perspective, Interventions, Comparison and Evaluation (Booth 2004) acronyms helped in the development of key words and phrases to be used in searching the relevant literature.

Examples of these key words/ phrases are using PICO and SPICE for the consideration of the research question “what are children’s experiences of asthma within primary schooling?”:

People: children (child, childhood child\$); teachers; parents/carers; school.

Intervention: asthma; chest infections; coughs and colds; pneumonia;

Comparison: those that do not have asthma, difference

Outcome: what it is like; managing; coping; having; education, performance, achievement, experiences, thoughts, feelings.

These key words/ phrases are using SPICE:

Setting: school; school trips; primary schools; pre-school;

Perspective: children's; parents'; teachers/ school staff's.

Interventions: managing; improving; helping; outcome, academic achievement; education, performance.

Comparison: those that do not have asthma; sibling differences.

Evaluation: effect upon well being, days absent from school; attendance; experiences, feelings, thoughts.

Electronic data bases were accessed in order to identify relevant academic research papers, these included health care related databases (for example Medline, CINAHL), education (ERIC) and psychological (EMERALD, PsychInfo) data bases since the subject area was located in a wide field of study.

The focus for each research question altered the key words chosen for the search of the literature, thus for example considering teachers and teacher's experiences of asthma management in school had different key words from the research question focussing upon school asthma policies. The literature search was executed with a separate focus at each run upon children, school staff and parents to ensure that the people that this research applied to were all considered and represented in this review of the literature.

Boolean operators ('and, or, not') were used such that search strategies were combined in order to reduce irrelevant journal articles. For example:

Database used	Search term	No. of hits
Medline	Asthma	115423
	children	618447
	Asthma and children	20481
	Asthma and children and schools	738

This could be further reduced from 738 by including research only published within the last ten years for example.

The above illustrates how papers were identified from searching electronic databases for one question in this thesis. Alternatively using \$ at the end of word such as school\$ generates the return of papers which had school, schools or schooling within their title this is known as truncation and is used when there is reason to suspect that there will be limited or little information revealed from using the key search term alone. The use of truncation and Boolean operators was applied following consideration of the initial number of hits achieved and discussion with subject and research specialist librarians within the faculty of health and life sciences at UWE.

This strategy was used for all five research questions and also to locate arguments centrally presented relating to child development and research methodologies used in this thesis.

Inclusion criteria for papers in this research was written in English (or English translation available), met the critical appraisal criteria (discussed on the next page) and the last date that this search strategy was run was August 2010. Thus papers published after this date would not be included since the literature review was by then completed.

Academic papers that were chosen to be cited in this research were selected following critical appraisal of the paper considering that critical appraisal is “the process of assessing and interpreting evidence by systematically considering its validity, results and relevance” (Parkes *et*

al. 2001, page 10). Critical appraisal tools such as that developed by Spencer *et al.* 2003 (available online) and the Critical Appraisal Tool for qualitative research studies developed by the Public Health resource unit at Salford University (CASP) (available on line) are two frequently used in the review of qualitative research. Quantitative research appraisal tools such as that suggested by 'Andrew Booth Critical Appraisal of the Evidence chapter in Gerrish and Lacey *The research process in nursing*', can be used in reviewing quantitative methods.

In this research the CASP qualitative critical appraisal tool, Booth's quantitative critical appraisal tool and for mixed methodology the suggested criteria for a good mixed methods research design of Teddlie and Tashkorri 2008 was used.

The selection of grey literature is discussed in appendix ii.

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Appendix ii: consideration of the use of grey literature from the world wide web in this thesis.

Increasingly the world wide web is providing reliable, accurate and credible information (Sim *et al.* 2007). Furthermore, search engines are used extensively to locate information that may be of relevance for the topic being considered. Consequently acknowledging that the world wide web can provide reliable information (please see section 2:1 in the thesis) it was deemed reasonable to use this as a method for searching for relevant information that may be suitable for inclusion into the main thesis. For example, a relevant and pertinent paper was only found via the search engine 'google' and using the key words 'childhood asthma in school', this was the report of a commissioned research conducted by the Office for Public Management in 2004 'Managing childhood asthma in schools'. Discussion with the authors of the research revealed that this report was not available through any other means apart from the world web wide, as it was a limited study commissioned by interested parties it could not be published in academic journals. However, the experiences cited by the children were valid and certainly this report needed to be included in this thesis.

However, it is important to consider how search engines operate, and once information/ papers is retrieved from the use of these search engines to critically appraise it using standard and accepted critical appraisal techniques as discussed in appendix ii. Table ii:1 below represents the key characteristics of how three search engines operate and can be used the table is reproduced (with permission) and adapted from Berkeley university library USA.

Search Engine	Google	Yahoo	Excelead
Size, type	IMMENSE. Size not disclosed in any way that allows comparison. Probably the biggest.	HUGE. Claims over 20 billion total "web objects."	LARGE. Claims to have over 8 billion searchable pages.
Noteworthy features	PageRank System includes hundreds of factors, emphasizing pages most heavily linked from other pages. Many additional databases including Book Search, Scholar (journal articles), Blog Search, Patents, Images, etc.	Shortcuts give quick access to dictionary, synonyms, patents, traffic, stocks, encyclopedia, and more.	Truncation lets you search by the first few letters of a word. Proximity search lets you find terms NEAR each other or NEXT to each other. Thumbnail page previews. Extensive options for refining and limiting your search.
Phrase searching	Enclose phrase in "double quotes".	Enclose phrase in "double quotes".	Enclose phrase in "double quotes".
Boolean logic	Partial. AND assumed between words. Capitalize OR. () accepted but not required. In advanced search partial Boolean available in boxes.	Accepts AND, OR, NOT or AND NOT. <i>Must be capitalized.</i> () accepted but not required.	Partial. AND assumed between words. Capitalize OR. () accepted.
+Requires/ -Excludes	- excludes + retrieves (e.g., +in)	- excludes + will allow you to search common words: "+in truth"	- excludes + retrieves (e.g., +in)
Sub-Searching	The search box at the top of the results page shows your current search. Modify this (e.g.,	The search box at the top of the results page shows your current search.	The search box at the top of the results page shows your current search.

	add more terms at the end.)	Modify this (e.g., add more terms at the end.)	Modify this (e.g., add more terms at the end.)
Results Ranking	Based on page popularity measured in links to it from other pages: high rank if a lot of other pages link to it. also invoked. Matching and ranking based on "cached" version of pages that may not be the most recent version.	Automatic	Popularity ranking emphasizes pages most heavily linked from other pages.
Field limiting	link: site: intitle: inurl: Offers	link: site: intitle: inurl: url: hostname:	intitle: inurl: site: after:[time period] before:[time period] (For details, click on "Advanced search")
Truncation, Stemming	No truncation within words. Automatically stems some words. Search variant endings and synonyms separately, separating with OR (capitalized): <i>airline OR airlines</i> Use * or _ as wildcards substituting for initials or words: <i>sickle * anemia</i> <i>george _ bush</i>	Neither. Search with OR as in Google.	Use * example: messag*
Language	Yes. Major Romanized and non-Romanized languages in	Yes. Major Romanized and non-Romanized languages.	Extensive language and geographic options. Use "Advanced Search".

Translation	Yes, in "Translate this page" link following some pages. To and sometimes from English and major European languages and Chinese, Japanese, Korean. Uses its own translation software with user feedback.	Available as a separate service	Yes, in "Translate this page" link following some page
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Table ii: 1 Characteristics of three search engines, and how to interrogate them to maximise the inquiry. (Adapted and reproduced with permission from University of Berkeley Library USA, available from <http://www.lib.berkeley.edu/TeachingLib/Guides/Internet/SearchEngines.html>)

Understanding how search engines operate allows some reasonable choice in the selection of which search engine to use and also in how to maximise the search engine's strengths to generate the best results.

For example, using 'google' and the key words asthma in schools children's experiences generated 22,900 000 results which are probably meaningless. However, using 'google' and the key words "asthma in schools, children's experiences" generated 27 scholarly articles which were all worth critically appraising and 7 were included in the literature review.

Caveats to be considered in reviewing web pages are:

Anyone can put up web pages, so they are less likely to be credible and peer reviewed so check who owns the domain (url address... a university, government body, NHS are more likely to provide reliable updated peer reviewed information).

Should be able to tell who wrote the information, when it was last updated, credentials of the owners , philosophy of the authors and reason for putting information upon the world web web;

Often there will be a link to published information (available in peer reviewed journals for example).

Finally once the above has been considered the information as discussed above must be critically appraised, before it is included.

References.

Sim,N.Z., Kitteringham, L., Spitz, L., Pierro, A., Kiely, E., Drake, D. and Curry, J. (2007) Information on the world wide web – how useful is it for parents? *J. Pediatr Surg* Feb: 42 (2): 305-12

University of Berkeley Library California USA (online)
available from:

[\http://www.lib.berkeley.edu/TeachingLib/Guides/Internet/Handouts.html#EvalForms accessed 20th August 2010]

Appendix iii: information and consent forms given to children and their parents.

The following pages include the consent forms given to the children and their parents, inclusion of children into this research required both the child and their parents to sign the consent forms.

The information sheets enclosed in this section are designed for two distinct audiences, the first is the children and they had a separate information sheet that was folded into three sections (as a leaflet) to read; the second is the information sheets designed for the parents/carers. Of course children and parents and carers could read both sources of information in order to decide whether or not to participate in this research.

The pages are reproduced at 75% of their original size to allow for binding.

The order of pages is:

Information sheet for children;

Information sheet for parents;

Consent forms.

Appendix iv: information sheets and consent forms for school staff.

The following pages contain in order, reduced to 75% of their original size to allow for binding:

Information sheets given to school staff;

Consent forms for school staff.

Appendix v: outline schema used in interviews with school staff.

This schema was loosely followed in the interviews, it provided a checklist to ensure that all interviews with school staff covered similar points. Although, the interviews with the school staff usually followed a much freer structure and as stated in the methodology were more akin to free narrative approaches used by Hollway and Jefferson (2000, 2008).

- Introductions (of both the researcher and school staff member(s)) and reaffirming purpose, consent, digitally recording of interview. Chance to ask and clarify any points relating to the research that they wished to ask.
- Can you tell me about how you manage pupil asthma in school?
 - Prompts include: do you know which children have asthma in school?
 - Does your school have a school asthma policy (or some such) to help manage children's asthma in school?
 - Do children have access to their inhalers?
- Can you tell me about a particular time/ incident when you had to manage children's asthma in school, perhaps when a child became unwell with their asthma or you had to make a decision to ask for help?
- What do you know about asthma and how it is managed?
- Is there anything you would like to help you manage asthma in school?

- Have you had training in managing pupil asthma?
 - can you tell me more about this?
 - What would you like it to include/ exclude?
- Is there anything else you would like to discuss?
- Any specific questions?
- Finalities....include thanking formally the member of school staff for their time, reminding them and assuring them that they would be given a transcript of their discussion and also their anonymity was assured.

Appendix vi: outline of the structure of the recorded interview with children.

These lasted between 50 and 70 minutes.

(Preparation pre commencement, involved significant organization of venue to maximize space and room for art equipment, often an area of the room was dedicated for introductions and story telling then the discussion would be in another area of the room and the 'best' location of the digital recorder identified).

Digital recorder switched on.

Introductions, these were from myself and then by the children. Reaffirming why the children were there (purpose of the research) and confirm their assent to participate.

Establishing engagement by the children this involved telling a story:

This story was "The Three Little Pigs", in a short rhymed text with detailed 'pop up' pictures.

Discussion was then introduced concerning the story, why it might have been chosen, whether or not the pictures were helpful in understanding the story and giving added detail. Most of the time discussion had commenced at the beginning of the story as the children ask questions and commented upon the pictures as they occurred.

Then the children were asked why they thought they were there and what they thought they would be allowed to do. Any

areas which needed exploration and discussion by the children were often addressed at this point.

Children were then instructed to choose an area (which was set out already with art equipment around it) that they would like to work in.

The children were asked to think about their asthma (but this had already been focussed upon in explaining why they were there and confirming assent to participate).

Following this direction, children discussed what they thought asthma was, or how they felt about having asthma in school. This initial direction for the children's discussion often arose following earlier questions and quite often children had things that they wanted to say or draw about concerning their asthma that had occurred to them early in the session.

Children were then allowed to draw/ create their art works and in doing this they discussed their asthma. The researcher spent time discussing asthma with each child in turn for five minutes at the commencement of their art work. Following this the researcher moved systematically between each child to ensure that each one had chance to discuss their views, however at times the children spoke freely between themselves about the task and this gave significant information and validation to statements raised by children.

Children were focussed upon the task as required, so if prompts were required these included:

Tell me about what it is like to have asthma at school?

What helps you manage your asthma in school?

How do you feel about having asthma?

Throughout the agreed time period children were focussed upon the task and given time and direction to complete their art work and participate in discussions.

15 minutes from the end the children were instructed to finish the picture they were drawing and as the children finished they were asked to discuss all the pictures that they had drawn and the child together with the researcher summarized (for each child) the key themes that the child had stated was important to them about having asthma at school.

At the end of the session each picture was digitally photographed and the child could take home their art work.

The children were all thanked verbally for participating in this research.

Digital recorder switched off.

At the completion of the research with the children each child was written to formally (upon university headed paper) and a précis of their key themes contained in the letter together with a formal thank you for their participation in the research was sent to them via the school.

Appendix vii:

The Paediatric Asthma Quality of Life Questionnaire –standardised version. PAQLQ(S).

23 Questions, reproduced with permission exactly from the original supplied by Professor E. Juniper. Inserted immediately following this appendix heading, including the children's response sheet and the choice of answers from either blue or green card.

Appendix viii:

Administration of the PAQLQ(S) in this research.

The research participants (children) had prior to this phase of the research (phase two) completed the qualitative stage of the research, phase one. Thus the children were known to the researcher and each other and had already a working relationship which allowed the questionnaire to be given in a supportive environment as dictated in the rubric upon the PAQLQ(S) for its administration.

The children were orientated to the purpose and reason for this stage of the research and their assent to participate was re-affirmed.

Suitable quiet rooms for the use of the PAQLQ(S) were found in each school. The time put aside for completing the questionnaire was a maximum of 45 minutes, it took children between 20 and 40 minutes to complete the task.

The children were sat in small groups of no more than four. Each child was sat on their own with two spaces between them and the next child to ensure that they were working independently, in a silent atmosphere. The children were reminded that there were no right or wrong answers, that it was their own thoughts and feelings that mattered. Each child had a copy of the answer sheet, the green and blue cards to refer to. The children were asked to place their ID number upon the answer sheet only.

The time frame was clearly identified (the preceding week), this was located usually by an activity from school, or identifying with the children if they could recall what had happened in the last week and identifying that activity as their terms of reference.

The questionnaire was read by the researcher, as dictated by the PAQLQ(S) instructions and the children asked to refer to the appropriate card to select their responses.

No help was given to each child or explanation of the question, even though this was frequently asked for by the children.

During the questionnaire and at the end the researcher could evaluate the children's answers and clarify any responses that were unclear, and review the answers for continuity as suggested by Juniper *et al.* (2004) to maximise the value of the PAQLQ(S).

The children were all thanked individually for their help and participation in this research.

Appendix ix: summary PAQLQ(S) data for each child research participant in phase two of this research.

For each child in schools one – seven the PAQLQ(S) score and the three sub-domain scores are presented below. The child’s unique identifier is purposefully not used, instead they are referred to in numerical order only within each school.

School One: overall PAQLQ(S) score 3.48

Child	PAQLQ(S)	Activity	Symptoms	Emotional
1	4.82	4.6	4.8	5
2	3.17	2.8	3.1	3.5
3	1.87	1.4	2.2	1.75
4	3.61	3.2	3.6	3.875
5	4.13	4	4.3	4
6	1.9	2	1.9	1.875
7	2	1.8	1.9	2.25
8	6.12	6.4	6.3	5.75
9	6.17	6.4	6.2	6
10	2.26	2.2	2.3	2.25
11	4.87	4.8	5	4.75
12	5.2	5.4	5.2	5.25

13	1.78	1.6	1.6	2.12
14	2.82	2.6	2.7	3.12
15	4.478	4.6	4.4	4.5
16	1.23	1.4	1.4	1
17	2.65	2.4	2.7	2.75

School Two: overall PAQLQ(S) score 4.08

child	PAQLQ(S)	Activity	Symptoms	Emotional
1	5.087	5.2	5	4.625
2	3.0435	2.8	2.9	2.875
3	6.454	6.2	6.4	5.875
4	3.0869	2.4	3.1	3
5	4.5217	5	4.5	3.625
6	5.912	6.4	5.6	5.125
7	2.9134	3	2.8	2.652
8	6.434	6.4	6.5	5.5
9	3.043	2.8	3.2	2.5
10	4.347	5.6	4.2	3.75
11	4.347	3.8	4.6	3.75
12	5.478	5.6	5.8	5
13	2.217	2.2	2.1	2.375
14	2.434	2.4	2.5	2.375
15	2.65	2.8	2.7	2.5
16	5.565	5.4	5.6	5.625

17	4.478	3.8	4.4	5
18	1.956	2	2	1.875

School 3: overall PAQLQ(S) score 3.86

Child	PAQLQ(S)	Activity	Symptoms	Emotional
1	4.869	5.6	4.6	4.75
2	2.21	1.6	2.6	2.125
3	5.95	6	5.9	6
4	3.69	2	3.6	4.875
5	4.04	4.4	3.7	4.25
6	5.22	5.2	5.1	5.375
7	2.56	2.2	2.7	2.625
8	6	6.4	5.9	5.875
9	3.6	3.2	4.2	3.87
10	3.6	3	3.5	4.12
11	2.695	2.8	2.7	2.625
12	4.174	4	4.3	4.12
13	1.69	1.2	1.5	2.25
14	4.98	5.8	4.7	4.75
15	6.43	7	6.2	6.375
16	2.65	2.4	2.7	2.75
17	1.61	1.4	1.7	1.625
18	5.17	5.8	5.1.	4.875
19	3.04	2.8	3.2	3

20	1.91	1.4	2	2.1
21	4.78	4.8	4.9	4.625
22	5.478	4.8	4.9	4.625
23	2.21	2.2	2.1	2.375

School Four: overall PAQLQ(S) score 4.93

Child	PAQLQ(S)	Activity	Symptoms	Emotional
1	3.478	2.2	3.9	3.75
2	6	6	5.9	6.125
3	2.565	2.87	2.12	2.4
4	4.869	4.1	4.5	5.1
5	6.391	6.1	6.7	6.4
6	5.91	5.7	5.8	5.4
7	1.78	1	2.2	1.8
8	3	3.4	3.2	3.0
9	4.65	4.2	4.7	4.9
10	6.4	6.2	6.7	6.0
11	6.26	6	6.7	6.5
12	5.39	5.1	5.5	5.0
13	3.65	3.2	3.7	3.1
14	4.89	4.7	4.8	5.0
15	6.26	6.3	6.2	6.1
16	5.045	4.8	5.2	4.9
17	5.13	5.4	5.1	5.2

18	5.61	6.0	5.1	5.5
19	6.434	6.0	6.6	6.9

School Five: overall PAQLQ(S) score 3.41

Child	PAQLQ(S)	Activity	Symptoms	Emotional
1	2.3333	2	1.8	3
2	3.375	4	2	4.25
3	3.217	5.2	5.2	6.625
4	3.695	3.8	3.6	3.5
5	2.65	2.4	2	3.625
6	2.434	2.6	1.8	3.125
7	3.39	2.8	3	4.25
8	2.34	2	2.6	2.25
9	4.217	5	3.2	5
10	3.17	2.8	2	4.87
11	4.69	4.2	4.7	5
12	2.52	2.6	2.5	2.5
13	4	5	3.4	3.625
14	3.82	5	3	4.125
15	2.91	3	2.9	2.875
16	3.39	3.6	3.3	3.375
17	3.61	5.2	2.9	3.5
18	1.87	1.1	1.9	1.87
19	5.78	5.8	5.8	5.6

20	6.43	5.6	6.2	6.6
21	1.61	2.1	1.8	1.4

School 6:Overall School mean 4.12

Child	PAQLQ(S)	Activity	Symptoms	Emotional
1	5.39	4.8	5.6	5.5
2	5.82	5.4	5.9	6
3	2.43	2.4	2.2	2.75
4	4.34	4.2	4.3	4.5
5	1.43	1.2	1.4	1.63
6	4.2	4	4.4	4.12
7	5.2	5.4	5.1	5.25
8	3.86	3.4	3.7	3.2
9	5.9	5.2	5.8	6.2
10	5.43	5.1	5.6	5.8
11	6.13	6.4	6.1	5.9
12	5.87	5.4	5.2	6.2
13	6.13	6.4	6	6.2
14	6.56	6.7	6.1	6.2
15	6.04	5.9	5.8	6.2
16	5.9	6.1	6.0	5.7
17	2	2.	2.	2
18	4.86	4.2	4.8	4.9
19	2.56	2.1	2.7	2.2

School 7: Overall School mean 3.94

Child	PAQLQ(S)	Activity	Symptoms	Emotional
1	3.685	3	3.4	3.25
2	6.13	6	6.1	6.25
3	3.21	3	3	3.625
4	5.45	5.2	5.3	5.75
5	2.345	2	2.5	2.375
6	5.608	6	5.9	5.125
7	3.13	2.8	3.2	3.25
8	2.26	2.2	2.2	2.375
9	2.56	2.6	2.6	4.25
10	5.69	5.8	5.8	5.5
11	2.17	2.2	2.6	2.4
12	2.17	1.98	2.4	2.1
13	4.608	4.35	4.2	4.1
14	5.869	5.2	5.1	6.0
15	2.478	2.4	2.8	2.1
16	1.608	1.4	2.2	2.0
17	2.565	2.1	2.7	2.8
18	1.869	1.9	1.6	2.1
19	2.347	2.1	2.0	2.5
20	6.217	6.2	6.7	6.4
21	5.478	5.1	5.2	5.6
22	3.652	3.45	3.6	3.7

23	5.739	5.2	5.1	5.9
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