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A MIXED METHODS INVESTIGATION OF PARENTAL FACTORS IN NON-ATTENDANCE AT  
GENERAL PAEDIATRIC HOSPITAL OUTPATIENT APPOINTMENTS

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## Aston University

A mixed methods investigation of parental factors in non-attendance at general paediatric hospital outpatient appointments

**Elaine Laura Cameron**

Doctor of Philosophy, 2014

Non-attendance at paediatric outpatient appointments results in delayed diagnosis and treatment, putting children at risk of avoidable ill health, and incurring considerable health service costs. Links between missed appointments and clinical, socio-demographic, and access-related factors have been indicated, but parental cognitions associated with non-attendance have yet to be investigated. The aims of this project were to evaluate the effectiveness and theoretical bases of existing interventions designed to reduce non-attendance; to consider the ways in which missed appointments are managed by healthcare providers; to explore parents' beliefs and experiences of attending and missing appointments; and to investigate the factors underlying these beliefs. A systematic literature review focusing on non-attendance interventions was conducted. Within a mixed methods framework, interviews were conducted with healthcare professionals, subsequent interviews were conducted with parents who had attended or missed a General Paediatric outpatient appointment, and a cross-sectional questionnaire study of parents' beliefs was implemented. The systematic review revealed that text message appointment reminders are effective at reducing non-attendance rates, but that no interventions have thus far been developed using theories of behaviour. Healthcare professionals recognised both barriers and parents' beliefs as influences on attendance, but also believed there were 'types' of families who miss appointments. Healthcare professionals disagreed somewhat about how non-attendance should best be managed. The parent interview study found six themes. The findings reflect parents' perceptions about the *importance* of attending and of their *ability* to attend. The results of the questionnaire study corroborate this structure of beliefs as the analysis produced two factors, the perceived 'worth' of attending and anticipated 'worry' when attending. This thesis demonstrates an original approach to investigating non-attendance at children's outpatient appointments, using mixed methods and adopting a psychological rather than service-use perspective. The findings contribute to Health Psychology theory and offer recommendations for healthcare providers.

**Keywords:** Paediatrics; outpatient services; mixed methods; parental health beliefs.

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## CHAPTER ONE

### 1. Introduction and literature review

#### 1.1 OVERVIEW

This thesis reports the design, implementation and findings of one systematic literature review and three empirical studies. Together these papers examine the occurrence and management of non-attendance at General Paediatric outpatient appointments and investigate the psychological factors associated with this problem. The main setting for the empirical research was Birmingham Children's Hospital NHS Foundation Trust (BCH) in the West Midlands region of the United Kingdom (UK).

The introduction chapter provides an overview of the definition of non-attendance and its prevalence, consequences and management in paediatric clinics. An explanation of General Paediatric services in the UK and a description of the research setting are also given. These are followed by a literature review of the factors associated with non-attendance, relevant theoretical perspectives, and an outline of the structure of the remaining thesis.

#### 1.2 BACKGROUND

##### 1.2.1 Describing and defining non-attendance

Non-attendance is a concept that is widely discussed in research articles, but is rarely accorded an explicit definition. The term is typically used to denote an occasion when a health appointment has been scheduled, but the patient has not arrived and has not contacted the clinic to cancel the appointment beforehand. Within the NHS, the equivalent term to describe a non-attended appointment is a 'did not attend' (DNA). The Health and Social Care Information Centre (HSCIC) provides an information standard for use by all individuals collecting or managing data in the NHS, and defines DNAs as instances when no 'care contact' took place and no advanced warning was given (Health and Social Care Information Centre, 2014). Though, it is unclear how far ahead of an appointment the patient must contact the clinic in order for it to be recorded as a cancellation rather than a non-attendance. The HSCIC guidelines importantly further differentiate cases where patients have arrived too late to be seen or where the appointment has been cancelled by the healthcare provider. In research articles however, it is often unclear whether late attendance is regarded as a DNA or not.

Furthermore, there are a plethora of alternative terms for non-attendance that occur in the research literature, including 'missed appointments', 'broken appointments', 'failed appointments', 'failures to attend', 'no-shows', 'absenteeism', 'poor appointment keeping', 'lost to follow up', 'non-

engagement' and 'forgone care', as well as generic phrases such as 'not going' and 'not turning up'. Expressions borrowed from the literature regarding adherence to medical treatment have also been used to describe missed appointments, such as 'non-adherence', 'non-compliance' and 'non-concordance'.

Much of this terminology conveys not only the non-completion of an expected action, but also negative connotations of breaking an agreement with a healthcare provider. The language therefore often appears accusatory or blaming of the patient. Roe (2010a) notes that the label DNA can be seen as derogatory or punitive. Accordingly, some authors (Powell & Appleton, 2012; Roe, 2010b) argue that the concept of non-attendance is inappropriate for use in paediatric settings where children themselves do not DNA, rather they are not brought by their parent or carer. The term preferred by these clinical academics is 'was not brought' or WNB, the use of which would purportedly prioritise the vulnerability of children and their right to access care (Powell & Appleton, 2012).

However, the expression 'was not brought' remains problematic as it implies parental wrongdoing and encourages criticism of parents, which may not be justified. In this thesis the terms non-attendance and 'missed appointments' will be used, or DNA where appropriate (e.g. when discussing NHS reported rates of non-attendance). Not only are these phrases the most commonly used, they are also arguably the most neutral. This is preferable when describing a behaviour for which the reasons and circumstances are often unknown to the researcher.

### **1.2.2 Prevalence of non-attendance in paediatric outpatient services**

In the year from April 2011 to March 2012 there were nearly 91 million outpatient appointments scheduled at hospitals in England, of which 6.8 million (7.5%) were not attended (Health and Social Care Information Centre, 2012a). Nine million of these scheduled appointments were for patients between the ages of 0 and 19. The DNA rate in this age bracket was 12.19% of expected appointments (i.e. excluding cancellations by the patient or hospital), or 1.25 million.

The Commission for Health Improvement (2003) recommends monitoring paediatric DNA rates, and in 2003 suggested that a figure between 10.1% and 13.5% should be considered average. Data for paediatric medicine and paediatric surgery at all health trusts in England at this time (2002-2003) shows that paediatric DNA rates ranged from 2.5% to 35.7% across the country, with a mean rate of 12.3% (SD 4.6) (Commission for Health Improvement, 2003). In this data set, Birmingham Children's Hospital had a non-attendance rate of 13.5%. More recent data regarding DNA rates at NHS trusts providing specialist children's care show non-attendance figures of 6.07%, 9.25%, 10.26% and 13.9%

at Great Ormond Street Hospital for Children (London), Sheffield Children's Hospital, Birmingham Children's Hospital and Alder Hey Children's Hospital (Liverpool) respectively (Health and Social Care Information Centre, 2012a). The difference between these two sets of data might suggest that the non-attendance rate at BCH has dropped by over 3%, however this divergence should be interpreted with caution as the latter figure includes all outpatient clinics at the hospital whereas the former includes general medical and paediatric surgery specialties only.

Research carried out in other countries across many paediatric specialty services suggests that non-attendance rates are highly variable, with figures up to 48% reported (Irwin et al., 1993; Oviawe et al., 1993). DNA rates are likely to be influenced by the type of specialty studied and the characteristics of the national healthcare system within which the clinic operates, as referral processes and access issues are likely to differ. For example, a research group in Israel found non-attendance to be between 30.5% and 33% for four different paediatric medical clinics, which were otolaryngology, dermatology, allergy and pulmonary services (Cohen et al., 2005; Cohen et al., 2007; Dreier et al., 2008; Goldbart et al., 2009). In comparison, three studies in the UK reported rates of 12% at a paediatric clinical genetics service (Holloway et al., 2010), 15.7% at an adolescent diabetes clinic (Snow & Fulop, 2012), and 17% at all medical outpatient appointments at a specialist children's hospital in Scotland (Brown et al., 1995).

Examining General Paediatric services specifically, much of the published research in the UK is now over ten years old with only two articles reporting rates in the past decade (McMillan & Jayatunga, 2012; Milne et al., 2006). Studies conducted prior to 2004 give average DNA rates ranging from 12.3% to 35%, with a mean rate of 26.4% across six articles (Andrews et al., 1990; Cooper & Lynch, 1979; Gatrad, 1997; Gatrad, 2000; McClure et al., 1996; Watson & Forshaw, 2002). In more recent publications, Milne et al. (2006) found an average rate of 10.6% non-attendance in medical paediatric clinics at a children's hospital in Scotland, though there was a large difference between new and follow-up clinics potentially due to differences in appointment booking systems (2.6% DNA at new appointments, 18.6% at follow up appointments). Similarly, McMillan and Jayatunga (2012) report a DNA rate of 9.23% at a General Paediatric clinic in a district general hospital (DGH) in the West Midlands while testing the usefulness of a sticker reminder system, suggesting that DNA rates may have reduced in the past ten to twenty years with the introduction of new booking systems and reminders.

One older paper reports the findings of a study carried out at Birmingham Children's Hospital and a district general hospital (DGH) in Birmingham between 1985 and 1987 (Andrews et al., 1990). The non-attendance rate reported in the General Paediatric clinic at BCH during 1987 was 30.5% (27% for

new appointments and 34% for subsequent appointments). However, modern data accessed directly from hospital records indicate that the DNA rate in the BCH General Paediatric service in 2010-2011 was 11.14% (Sheinmar, 2012). From the available data it seems that paediatric non-attendance has decreased nationally and at BCH over the past thirty years. However, both rates remain unacceptably high at over 10%.

### **1.2.3 Consequences of missed appointments**

Missed appointments have negative consequences for patients, families and healthcare providers, which may result in poorer health outcomes for children and inefficient paediatric services. First, there are direct costs to NHS organisations through lost revenue. Data from the healthcare information provider, Dr Foster Intelligence, indicates that the average income to an NHS hospital of a first outpatient appointment was £156 in 2007-2008, while a follow up appointment generated approximately £76. With 6.5 million hospital appointments missed that that year, it was estimated that outpatient non-attendance cost the NHS more than £600 million between 2007 and 2008 (Dr Foster Intelligence, 2009). Slightly lower rates of 5.8 million DNAs and a cost of £585 million were reported in the year 2011-2012 (Dr Foster Intelligence, 2012, p.25). Considering that paediatric general medical appointments constituted 2.7% of all attended appointments in 2011-2012 and all outpatient appointments for 0 to 19 years olds constituted 12.4% (HSCIC, 2012b), it is reasonable to estimate losses of potential revenue of £15.6 million through non-attendance in General Paediatrics and £72.4 million through all outpatient appointments missed by children and young people.

Bech (2005) calls this loss of income the 'financial cost' of non-attendance, and distinguishes this from 'social costs', which are defined as the "lost value of the unused or misused resources resulting in lower productivity and lost benefits" (p.184). Cited social costs include unused staff time, equipment and clinic capacity, longer waiting times in clinics, and patients waiting longer for health services (Bech, 2005). This "waste of time and resources" is highlighted by many authors (e.g. McClure et al., 1996) and both Detman & Gorzka (1999) and Pesata et al. (1999) emphasise the latter point, that missed appointments reduce the opportunity for other families to receive timely care. It has also been argued that non-attendance is a barrier to junior doctor education which requires practice in doctor-patient interaction and relationship building through continuity of care (Hixon et al., 1999). Moreover, missed appointments can lead to clinician frustration and consequent decreases in the quality of communication with families and the amount of empathy shown (Pesata et al., 1999).

Equally concerning are the potential consequences of non-attendance for children's health. There are few studies that directly examine the effect of missed appointments on health outcomes given the difficulty of differentiating effects from other influencing factors and accessing non-attending patients for participation. However, there is some evidence to suggest that missed appointments can be detrimental to health. Andrews et al. (1990) assessed the health of 34 children who had missed General Paediatric appointments at a DGH in Birmingham, UK. They concluded that 21 children still required medical attention, including GP care (n=2), diagnostic tests (n=8) and hospital outpatient treatment (n=11), thereby putting them at risk of avoidable ill health. However, the authors do not state for which conditions care was still recommended or how long after the DNA the children were assessed, so it is not possible to judge whether these figures reflect short or longer term outcomes, as some conditions are self-resolving.

Studies of children and young people with specific conditions provide further evidence of negative effects of non-attendance on health. Masding et al. (2009) report that in a UK transitional diabetes clinic, where care is delivered by both paediatric and adult healthcare staff, young people who had missed at least one appointment had a significantly higher HbA1c level than those who had attended all appointments ( $p < .001$ ), indicating poorer metabolic control. However, the results are based on retrospective audit and correlational data only meaning that causation cannot be inferred. It may be the case that patients with poor control of their diabetes are also more likely to miss their diabetes clinic appointments. Kofoed et al. (2010) somewhat overcame this deficiency in study design by taking advantage of a two month national nursing strike in Denmark to evaluate changes in blood glucose levels of children and young people with diabetes whose care was delayed due to clinic closure. In a sample of 155 patients it was observed that mean HbA1c levels at two visits after the strike were significantly higher than two visits before the strike ( $p < .0001$ ), and the effect was most discernible in children who had well controlled blood glucose before the strike. In an additional survey of families as part of this study, 49 parents (43.3%) stated that their children's diabetes had deteriorated as a result of the clinic closure. These findings suggest that delays in follow-up care, whether due to patient non-attendance or provider cancellation, can have measurable effects on children's health outcomes when appointments are necessary to assist with condition management. These studies which were carried out in paediatric and adolescent secondary care services contradict the findings of Bigby et al. (1984) who reported no significant differences between attenders and non-attenders at an adult primary care centre in the USA, in terms of development of new medical problems or the exacerbation of existing problems. This demonstrates that caution is necessary when applying results obtained outside of paediatric secondary care to children in outpatient services.

A final piece of evidence regarding the seriousness of missed appointments for children's health comes from a confidential enquiry reviewing avoidable factors in child mortality (Pearson, 2006). The report describes several cases of child death where children had not attended appointments and were not adequately followed up by healthcare professionals. One example given was that of a girl with poorly controlled asthma who ultimately died of an asthma attack. The review saw a letter from a consultant who stated that the child had missed two consecutive outpatient appointments and would therefore be taken off the clinic list as per the hospital policy. This example demonstrates that missing appointments can result in, or facilitate, devastating consequences when they remove opportunities for healthcare professionals to recognise and remedy severe health problems. It also highlights that in some organisations multiple DNAs lead to patients being 'struck off' and not receiving any further appointment offers, meaning that care is discontinued and the threat to health is heightened. As such, the confidential enquiry report states that, "Whilst there may be policies in which adults are not sent repeat appointments, this will rarely be appropriate practice with children" and that non-attending children should be followed up "pro-actively" (Pearson, 2008).

#### **1.2.4 Non-attendance and child protection issues**

The previous section illustrates that missed appointments are concerning because of the potential negative outcomes for child health. However, it is argued that they are also worrisome as they can be seen as indicators of possible child protection issues. Powell and Appleton (2012) emphasise that children have a fundamental right to access healthcare services and to enjoy "the highest attainable standard of health", as declared by the United Nations Convention on the Rights of the Child (1989). Therefore when parents fail to bring children to appointments it can be considered a form of child neglect, and in some cases can even be a marker of serious abuse or maltreatment (Powell & Appleton, 2012). This is supported by NICE guidelines on 'When to Suspect Child Maltreatment' (2009), which state that failure to seek medical advice and repeated failure to attend 'essential' appointments, to the extent that the child's health and wellbeing are compromised, should be grounds for considering neglect (p.23). The UK National Service Framework for Children, Young People and Maternity Services (NSF) (Department for Education and Skills & Department of Health, 2004) takes a less forthright stance and observes merely that missed appointments may trigger concern and indicate "a family's vulnerability, potentially placing the child's welfare in jeopardy" (core standard 3, point 7.6, p.97). Whether neglectful, deliberately harmful or a sign of family incapacity, missed appointments raise questions about the safeguarding of children and young people.



In all cases, responsibility for protecting the welfare and wellbeing of children has been placed squarely with healthcare professionals. Guidance from the General Medical Council (2012) states that protecting children and young people is, “the responsibility of all doctors” and similar guidelines from the Scottish Government say that, “In circumstances where the child is denied [health] services by their parents/carers, healthcare professionals including GPs must consider that it is their professional responsibility and duty to act on the child’s behalf” (p.71). The NSF recommends that local systems are developed to ensure that General Practitioners (GPs) and other referrers are aware when a child patient has not attended an appointment for specialist care, and can take follow up action as appropriate (Department for Education and Skills & Department of Health, 2004, core standard 3, p.98). In addition, the Care Quality Commission (2009) now stipulates that all NHS Trusts should have processes in place for following up children who miss appointments as part of their child protection policies, after it found that 32% of NHS hospital Trusts and 49% of Primary Care Trusts (PCTs) had no such process in place.

This thesis is primarily concerned with the prevention of non-attendance, through elucidating the factors that influence whether an appointment is attended or not and considering interventions that might address these factors. An examination of the myriad ways in which child protection issues are played out via children’s use of healthcare services is outside the scope of this project. However, fewer missed appointments would mean more opportunities for healthcare providers to assess the wellbeing of child patients and to identify and assist vulnerable families. Moreover, if fewer appointments are missed as a result of ‘innocent’ causes, such as forgetting, poor access, or lack of communication, then it may be easier for clinicians to detect instances of non-attendance that ought to raise concern.

#### **1.2.5 Current guidelines for management of non-attendance**

There are no overarching national directives aimed primarily at preventing and managing non-attendance either in adult or paediatric care in the UK. However, as noted above, there have been several governmental and health guidelines that recommend active follow up of children who miss appointments, mainly to meet child protection responsibilities (Department of Education and Skills & Department of Health, 2004; Pearson, 2008; Scottish Government, 2013). Indeed, the Care Quality Commission (2009) has stipulated that, “All trusts must have clear policies for safeguarding and promoting the welfare of children... There are key elements that should always be covered in the child protection policy... [including] a process for following up children who miss outpatient appointments” (p.18).

These documents address missed appointments that have already occurred, but with regards to *preventing* non-attendance or reducing DNA rates there are fewer guidelines. Though, the NSF (Department for Education and Skills & Department of Health, 2004) advocates that healthcare providers should review their DNA rates to ensure that the needs of children and young people are being met (p.98). A quality and service improvement tool published by the NHS Institute for Innovation and Improvement (2008) gives more specific instructions for healthcare providers, suggesting four steps for reducing 'did not attends': determining whether there is a higher than acceptable DNA rate, determining the causes of non-attendance at the particular organisation, understanding the patient profile to make attending as easy as possible, and attempting some of the suggested DNA reduction strategies, such as reminding patients, decreasing patient anxiety, and making sure the appointment is necessary.

There has also been at least one NHS-wide initiative in recent years that includes effect on DNA rates as one of the anticipated outcomes. The 'Choose and Book' referral system was designed to improve the experience of patients and families by giving them a fully confirmed appointment at the time of referral at a hospital of their choice, and at a time convenient for them. Choose and Book referrals are made directly by the family or with the help of their GP, either online or over the telephone. The Department of Health (2004) policy framework for implementing Choose and Book explicitly stated that, "Secondary care [services] will... see a reduction in the volume of Did Not Attends (DNAs) and cancellations because patients will agree their date and time." There has been mixed evidence regarding the achievement of this aim, with a study of adult urology referrals finding higher DNA rates in patients scheduled via Choose and Book compared to those booked by traditional GP paper-based referrals (Pisipati et al., 2009). Conversely, Parmar et al. (2009) report that there was significantly better attendance in patients referred to an audiology clinic by Choose and Book than by standard referral. There have been no studies examining the effect of the Choose and Book referral system on non-attendance conducted solely in paediatric outpatient services.

### **1.2.6 An overview of General Paediatric outpatient care**

General Paediatrics is a consultant-led, secondary care specialty delivering general medical assessment and treatment to children and young people, typically up to the age of 16 in the UK. It is defined as, "the diagnosis from symptoms, signs, and investigations, of undifferentiated referred infants, children and young people" (Wacogne et al., 2006). A key term in this definition is 'undifferentiated', meaning children presenting with problems that are "ambiguous, uncertain, unexplained and undiagnosed" (Royal Australian College of General Practitioners, 2011) and that are non-organ specific, making them unsuitable for referral directly to a medical sub-specialty such as

Paediatric Cardiology or Paediatric Oncology. The definition also includes the term 'referred', indicating that access to General Paediatric care is usually through referral from a GP or other healthcare professional, including referrals from different secondary and tertiary level services. Some patients also come to receive General Paediatric care following a visit to the emergency department, either by referral or after being admitted to hospital. General Paediatricians provide inpatient as well as outpatient services, and so may see some patients on the ward prior to outpatient appointments. General Paediatrics is mainly provided in DGHs and specialist centres such as BCH, but can also be delivered in community settings.

The second part of the definition offered by Wacogne et al. (2006) states that, "The General Paediatrician then initiates treatment which can be delivered personally or by another person or team, according to the needs of the child." This illustrates the child-centred focus of General Paediatric care, a central tenet within the specialty training of General Paediatricians (Royal College of Paediatrics and Child Health, 2008). It also highlights the need to work collaboratively with other healthcare professionals to meet the best interests of the child. The Royal College of Paediatrics and Child Health (2012) notes that, "Sick children can have simple or complex diseases and the paediatrician needs to know how to manage these independently or by working with other colleagues." This means that in some cases it will be most appropriate for treatment to be administered by the child's GP with advice and support from the General Paediatrician, some children will be referred onwards to other specialist services, and some children with complex or long-term health needs will receive continuing care in the General Paediatric clinic. This comprehensive definition accords with the classification of outpatient care proposed by the Clinical Standards Advisory Group (2000), which suggests that outpatient services can be "explicitly and legitimately requested" (Dodd & Newton, 2001) in order to receive advice, continuing care, access to procedures, investigations or treatment not available in primary care, or reassurance including "the 'ritual' and 'pilgrimage' effect of consulting a specialist" (Dodd & Newton, 2001).

There have been five epidemiological studies of referrals to General Paediatric services conducted in the UK in the past 25 years (Blair et al., 1997; Holmes & Ni Bhrolchain, 2002; MacFaul & Long, 1992; Ni Bhrolchain, 1992; Thompson et al., 2011). The most recent of these studies describes the case mix of referred conditions and reasons for referral in new patients to a DGH General Paediatric service in 2006, and compares this to findings from 1988 obtained at the same institution and using the same methods (Thompson et al., 2011). The authors report that the referral rate had increased significantly from 15.5 to 25.7 per thousand children under the age of 15 per year, and that the profile of conditions seen had changed over the course of the interim 18 years. The most common

conditions referred in 1988 were asthma and heart murmurs, whereas in 2006 the most common were constipation, enuresis (bedwetting), urinary tract infection, and food allergy. No food allergy referrals were made in 1988. The changes are also reflected in the recorded reasons for referral which show that the main reason given in 1988 was to “make a diagnosis”, but in 2006 was to obtain “advice on management.” The top ten condition categories seen by General Paediatricians in 2006 in this study were gastrointestinal, behavioural, urinary, developmental, respiratory, neurological, cardiovascular, infective, allergenic, and periodic syndrome (i.e. cyclical vomiting and migraine) (Thompson et al., 2011). These findings show the breadth of conditions seen typically in a General Paediatric clinic, making General Paediatricians “experts in the broadest range of conditions” (Birmingham Children’s Hospital, 2013a).

Although the case mix of a General Paediatric service includes behavioural, social and developmental problems, it should be noted that many such cases might be referred preferentially to the related specialty of Community Paediatrics. Community Paediatricians are responsible for seeing and treating children with long-term disabilities, such as cerebral palsy; learning disabilities; mental health issues, including autism and attention deficit disorders; children for whom there is suspicion of maltreatment; and children who are being fostered or adopted (Royal College of Paediatrics and Child Health, 2014). Conditions or circumstances such as these are therefore less likely to be seen in General Paediatrics, except as secondary conditions.

### **1.2.7 The research setting – Birmingham Children’s Hospital**

Birmingham Children’s Hospital NHS Foundation Trust delivers paediatric healthcare across two sites in Birmingham in the West Midlands, UK. The main hospital site in Birmingham city centre provides paediatric medical, surgical, specialised and clinical support services, as well as paediatric emergency medicine, while the Parkview Clinic located in south Birmingham provides child and adolescent mental health services. Services are delivered at regional, national and international levels, with 34 specialities and 11 nationally commissioned services. The hospital has over 240,000 patient visits a year, with 150,000 of these being outpatient visits (Birmingham Children’s Hospital, 2013b).

The General Paediatric service at BCH provides a secondary care referral service to GPs of children primarily in central and south Birmingham. However, with the introduction of Choose and Book it is likely that referrals will now more frequently be received from other localities in the wider Birmingham area. The demographic and health profile of children in Birmingham has been assessed by the Child and Maternal Health Observatory (2013) who report that children and young people (under the age of 20) make up 28.8% of the city’s population. Approximately 63% of school children

are from a black or minority ethnic group, and 33.5% of children under the age of 16 are living in poverty. This means that the health of children in Birmingham is generally poorer than the average for England. This includes higher than average infant and child mortality rates. Moreover, 11.9% of children aged 4 to 5 years old and 24.3% of children aged 10 to 11 are classified as obese (Child and Maternal Health Observatory, 2013).

There are twelve consultants delivering the General Paediatric service at BCH, as well as one paediatric specialist nurse. In addition to working on inpatient wards and providing outpatient appointments at the main BCH site, the General Paediatric team also offer clinics at two community-based outreach settings. These 'satellite' services were set up in 2006 and 2010 at a health centre in east Birmingham and a Sure Start children's centre in south Birmingham respectively. Both clinics serve relatively deprived areas. The main purpose of these outreach clinics was to provide improved access to care for families in these localities, which it was hoped would reduce the rate of non-attendance at General Paediatric appointments (Heath, 2013). An evaluation of the pilot service initiated at the clinic in east Birmingham in 2006 found a reduction in DNA rate at the outreach clinic compared to the main BCH site (10% vs 30%) (Buckle, 2007). However, more recent data and anecdotal reports indicate that non-attendance may now be higher at the outreach clinics than the main site (Heath, 2013). Though, direct comparison is somewhat difficult given the much smaller number of families scheduled to attend the community-based clinics and confounding factors, such as differences in conditions seen, and differences in the distribution of deprived and ethnic minority families at each site.

Since 2010 BCH has also gradually introduced a text messaging service to remind families of their appointments and reduce DNA rates. A formal evaluation has not been carried out, but in the year 2009-2010 the non-attendance rate in General Paediatrics was noticeably higher than at present, with 28.1% non-attendance at new appointments and 13.7% at follow up appointments (total 17.12% of all expected appointments) (Birmingham Children's Hospital, 2010). Again, objective assessment of this strategy is difficult as reminders were not universally rolled out across the Trust or across the General Paediatric service at one time point. Rather, the approach seems to have been applied incrementally.

Finally, in compliance with the recommendations of the Care Quality Commission (2009), BCH has a Trust-wide DNA policy (Birmingham Children's Hospital, 2009) that provides guidance for managing missed appointments that have occurred. The stated purpose of the document is to reduce DNA rates, maximise appointment slots, and ensure patients are seen in a timely manner, while balancing the need to maintain adequate child safeguarding. The policy is based on the principles that the

family has been given an appropriate time and date for their visit with sufficient notice, that the letter has been sent and received, and that the family has clear instructions regarding who to notify if they need to cancel or reschedule the appointment. In the case of missed new appointments the policy stipulates that the child's GP is to be informed in all cases and that the offer of another appointment is at the discretion of the consultant. If a second appointment is offered and not attended the GP would be asked to review the need for the appointment. A third appointment would only be offered in exceptional circumstances, and if a third DNA occurred then the GP would be asked to refer the child elsewhere. In the case of missed follow-up appointments, consultants must either issue a new appointment, contact the GP to confirm if an appointment is still required, or inform the GP that no further appointment has been offered and a re-referral would be necessary if the family still wanted or needed to be seen.

In depth examination of each of these initiatives at BCH (outreach clinics, text message reminders, and the DNA policy) is outside the scope of this project. However, qualitative data regarding attendance at outreach clinics in comparison with attendance at the main hospital has been collected from both parents and staff as part of the studies presented in this thesis. This data has been analysed separately and will be published elsewhere. Instead, only general themes relevant to attendance at all sites will be presented. Similarly, although reminders and the DNA policy were not major foci of this research, both aspects were mentioned by participants in the two qualitative studies. This data has been used and presented where appropriate.

### **1.3 LITERATURE REVIEW**

This section reviews the literature regarding factors associated with non-attendance at General Paediatric outpatient appointments. Previous observational research has investigated a range of factors, including socio-demographic variables, difficulties accessing services, appointment-related factors, and perceptions of the child's health status. These factors will be considered in turn before describing the findings of two papers presenting parent-reported reasons for non-attendance. The review focuses primarily on research conducted in General Paediatric settings in the UK, but additional literature is utilised where appropriate. It is important to note that some literature has been deliberately excluded as insufficiently related to the context of interest, General Paediatric appointments. Excluded studies include those conducted in paediatric psychiatry and dental services, and in children's primary care or health promotion settings (e.g. for screening or immunizations). Although the reasons for non-attendance in these settings may overlap with those in medical services, it is likely that parents' behaviour in these contexts will be heavily influenced by additional factors, such as fear of dental care, stigma surrounding mental health issues, concerns about

childhood vaccinations, and perceptions of importance and ease of access to primary care appointments. Attendance at a parent-initiated primary care appointment is likely to be driven by different factors than attendance at an appointment recommended by a GP or other healthcare professional meaning that studies in primary care have been omitted. This includes studies conducted in the USA or countries with similar healthcare systems, as paediatricians in the USA are often primary-care physicians that work within hospital or private settings rather than exclusively referral-based services. Literature is therefore limited to countries with healthcare systems similar to the UK.

### **1.3.1 Socio-demographic factors**

The age of the child was found to be associated with attendance at a UK General Paediatric clinic in a study by McClure et al. (1996) who found that non-attending children were significantly older than attending children, with a mean age of 78 months compared to 64 months. However this finding was not supported by Cooper and Lynch (1979), who found no association between age of the child and persistent failure to attend. McClure et al. (1996) also reported no correlation between parental age and attendance, though Cooper and Lynch (1979) noted a tendency for parents of persistent non-attenders to be younger than attenders.

No association was found between the gender of the child and non-attendance (Cooper & Lynch, 1979; McClure et al., 1996). Gatrad (1997), however, reported gender differences in attendance in a specific group, as Muslim boys were found to miss more appointments than Muslim girls. Gender differences were not observed in other religious or cultural groups. Ethnicity as an individual factor was found to be unrelated to failure to attend in two studies (Cooper & Lynch, 1979; Gatrad, 2000), though an earlier study prior to implementation of culturally relevant clinic booking strategies showed a difference in attendance between English and Asian families at a General Paediatric clinic in the West Midlands (Gatrad, 1997). Asian families were significantly more likely to miss appointments than English families, at both new and follow up appointments. Downer et al. (2011) also found an effect of native language on attendance rates in the outpatient department of a specialist children's hospital in Australia, with non-English speaking families significantly more likely not to attend.

A strong predictor of non-attendance appears to be socio-economic status. McClure et al. (1996) noted that a larger percentage of non-attending families were classified as social class IV or V, indicating high deprivation, and Downer et al. (2011) found that families in lower socio-economic groups were more likely to miss appointments. In a study of paediatric ophthalmology appointments,

Bowman et al. (1996) found a significant difference in the percentage of children attending a first appointment from postcode areas classed as low deprivation compared to those from areas of greater deprivation. Holloway et al. (2010) similarly showed that higher deprivation was associated with greater likelihood of non-attendance at a paediatric genetic counselling service.

Cooper and Lynch (1979) reported that 58% of non-attending children were classified as coming from families with diffuse social problems (i.e. where the family as a whole is affected by several long-term problems, such as parental unemployment), compared to only 16% of attending children. Watson and Forshaw (2002) further reported that 218 out of 685 non-attending children (31.8%) were known to social services, of which 38 (5.5%) were on the child protection index and 8 (1.2%) were on the child protection register. Though, the distribution of these variables in the attending patients was not compared to check for significant differences.

### **1.3.2 Factors related to accessing services**

Mode of transport to the appointment may have an effect on likelihood to attend. Participants who had attended their appointments in the study carried out by McClure et al. (1996) specified travel by car as the most common means of transport to the clinic (63%). This was in contrast to non-attending participants who reported that they would have travelled by car in only 37% of cases, more often specifying travel by public transport or walking. The same study found that although there was no significant difference in the average distance to the clinic for attenders and non-attenders, there was a significant difference in the journey time from home to clinic. Non-attenders' journey times were found to be on average 7.4 minutes longer than attenders (35 minutes versus 27.6 minutes), which may be a reflection of the modes of transport used (McClure et al., 1996). However, it should be noted that journey times were self-reported, meaning that non-attenders may have overestimated, either consciously or unconsciously, the time taken to get to clinic in order to reinforce the justification for their non-attendance. Furthermore, non-attenders filled in the study questionnaire at least two weeks after their last appointment, while attenders filled in the questionnaire at the clinic appointment. Thus, attenders may have been able to provide more accurate estimates of their journey time. This finding should therefore be interpreted with caution.

In contrast, a study carried out in a Community Paediatric population with families of children who were on the Special Needs Register did find an effect of distance on attendance (Cordiner et al., 2010). A greater return distance from the patient's home to the clinic was related to a greater number of missed appointments by that patient. This could be attributable to greater difficulty in travelling with a child who has additional needs. However, given that many patients attending



General Paediatric clinics may also have additional support needs, it is not unreasonable to conclude that families in a General Paediatric context may also find distance to the clinic a barrier to care. Research conducted in an Australian context found that increased distance from the clinic improved attendance (Downer et al., 2011), but this finding may not be directly transferable to UK settings given the differences in size of referral areas and hospital catchment populations between the two countries.

### **1.3.3 Appointment-related factors**

The rate of missed appointments has been found to vary greatly depending on the specialty of the clinic and whether the appointment is a first or follow-up appointment. Andrews et al. (1990) reported that non-attendance in cardiology and oncology clinics were as low as 6% for first-time appointments and 13% and 17% for follow-up appointments, compared to rates of 32% and 49% at first and follow-up appointments in an orthopaedic clinic, suggesting that appointments are more likely to be kept in specialist clinics where children might be expected to have more serious or life-threatening conditions. This difference between specialties has also been demonstrated by McClure et al. (1996) who reported an average non-attendance rate of 27% at specialty clinics with a large standard deviation of 19.1%, suggesting much variation in attendance rates. The same study reported a 25% non-attendance rate at General Paediatric clinics with a standard deviation of 9.5%. Andrews et al. (1990) found that an average of 24.3% first-time appointments and 34.7% follow-up appointments were missed in a General Paediatric cohort. As mentioned previously, the BCH data for 2009-2010 showed the opposite pattern where more first appointments were missed than follow up appointments (Birmingham Children's Hospital, 2010), suggesting that the relationship between appointment type and likelihood of attendance is not yet clear.

Two studies reported a positive correlation between the number of appointments a family was scheduled to attend and their likelihood to miss an appointment. McClure et al. (1996) showed that those who missed appointments had significantly more scheduled visits in the previous year than those who attended their appointments. Similarly, it was reported by Cordiner et al. (2010) that missed Community Paediatric appointments were more likely to occur in the half of their sample that had the greatest total number of allocated appointments from the hospital and community. It should be noted, however, that families in their sample may have had an unusually large number of total appointments, given that the families involved in the study included children on the Special Needs Register, and that attendance at all of these appointments may have been particularly difficult for families of children with additional needs.

There is also some suggestion that previous non-attendance at appointments is related to subsequent non-attendance. McClure et al. (1996) found that 85% of attenders had also attended their last appointment, compared to just 55% of non-attenders. Attendance was also found to be significantly related to the length of time families must wait between scheduling an appointment and the visit itself, with longer waiting times resulting in poorer attendance in two studies (Bowman et al., 1996; Downer et al., 2011). The source of the appointment referral also appears to be important for attendance, with 64% of non-attenders having first attended the emergency department compared to 22% of attenders (Cooper & Lynch, 1979).

#### **1.3.4 Perceived severity of the child's health condition**

Andrews et al. (1990) found significantly greater attendance at specialty clinics for conditions that might be perceived as more serious, such as oncology and cardiology, compared to clinics for "non-life threatening" conditions such as orthopaedics. The authors therefore suggest that parents might be more likely to attend if they perceive their child's condition to be more severe. However, the converse of this relationship was found by McClure et al. (1996) who showed that parents who did not attend a General Paediatric appointment perceived their child's illness to be more serious than those parents of attending children. Severity of the illness of non-attending children was also rated higher than attending children by the clinician. Additionally, more non-attenders than attenders were deemed to have additional medical problems in the study by Cooper and Lynch (1979), suggesting that non-attending children may indeed be more seriously ill than those who attend.

#### **1.3.5 Predisposing parental factors**

An unpublished systematic review of factors associated with non-attendance at paediatric health appointments in the UK (Oyebode & Cummins, 2010), supplemented by further reviewing of the literature for this thesis, found that only the aforementioned factors related to socio-demographics, access, appointments and child health status have been addressed in published observational studies. However, literature scoping from non-medical, non-UK, primary care and adult services suggests that there may be additional individual factors that predispose families to miss health appointments. For example, parents' mental health issues, drug and alcohol use, and health literacy.

Several studies indicate that mental health issues of parents or patients can influence attendance at appointments for a variety of services. Jhanjee et al. (2004) reported that non-attendance at 'well-child' clinics in the USA was associated with parents' symptoms of depression, while Gordon et al. (2010) found that history of maternal depression was the most powerful predictor of non-attendance at paediatric psychiatry appointments. Moscrop et al. (2012) showed that young adults who did not

attend primary care appointments in an English sample were significantly more likely to have presented with mental health problems in the past, or to present with them in the twelve months following the missed appointment. Substance use has also been shown to be a predictor of attendance at appointments, with Howe et al. (2014) reporting that untreated 'at-risk' alcohol and drug use was associated with non-attendance at HIV clinics. Similarly, in a study of adolescents with HIV in the USA, Dietz et al. (2010) found that marijuana use was associated with missed appointments.

Health-related knowledge and ability to find and use relevant information to make health decisions may also be important predictors of attendance behaviour. Holtzman et al. (2014) investigated non-attendance at adult dental appointments and found that patients who accessed fewer sources of health information and had lower oral health literacy were more likely to miss appointments. Moreover, a study conducted in an adult psychiatric outpatient department reported that patients with lower 'Functional Health Literacy' scores also exhibited lower adherence to appointments (Bizamcer & MacIntyre, 2011). These studies in diverse settings highlight that there are a range of individual parental and patient-related factors that have not yet been investigated in relation to attendance at children's medical outpatient appointments.

### **1.3.6 Summary of observational studies**

Studies investigating the predictors of attendance at General Paediatric outpatient appointments present numerous factors that may influence attendance. However, few of the factors were investigated by more than one or two studies. It is therefore difficult to assess whether these findings are applicable beyond the original setting. In cases where factors were investigated by more than one study, there was some disagreement over the findings. For example, the age of the child was found to be predictive of attendance in one study (McClure et al., 1996), but no such relationship was found in a second study (Cooper & Lynch, 1979). Socio-economic status was found to be significantly related to attendance in three studies, suggesting that this may be an important risk factor for non-attendance. However, the reasons why families from lower socio-economic groups are less likely to attend are not clear. The influences of separate components of socio-economic status, such as education and income, have not been investigated. In contrast, it was reported by two different studies that ethnicity is not related to attendance (Cooper & Lynch, 1979; Gatrad, 2000), suggesting that access barriers experienced by particular groups have less influence on attendance than predominant factors that are common across cultural and ethnic groups.

It is clear from the literature that the factors related to non-attendance at General Paediatric outpatient clinics are numerous and interconnected. However, the specific mechanisms by which these factors influence attendance and the relationships between the factors have not been widely investigated, and there are numerous variables which have yet to be evaluated in relation to this type of service. Moreover, much of the existing research may now be outdated as many of the relevant studies were conducted more than ten years ago. Further research is required to establish the veracity of the reported findings and to extend the literature beyond mere description of the relationships between individual factors and attendance, to elucidation of the processes by which these factors have their effects.

### **1.3.7 Parent-reported reasons for non-attendance**

Few studies have investigated the reasons that parents themselves give for missing children's outpatient appointments in a UK context. However, the little research that has been carried out supports and augments the correlational findings reported above. An interview study carried out with 120 Muslim families who had failed to attend a paediatric outpatient appointment in the preceding twelve months revealed that predominant reasons (specified by 20% of participants) for non-attendance included limitations due to religious traditions, for example fasting during Ramadan and observing religious holidays (Gatrad, 1997). In the same sample, 17% of families cited communication difficulties as a reason for not attending. In the majority of studies described above, ethnicity was not found to be a significant predictive factor of attendance. However, these findings suggest that families from minority ethnic groups may have distinct needs and considerations, which may make access to appointments more difficult.

A second study suggests that the decision to attend may also be influenced by individual family circumstances. Andrews et al. (1990) carried out semi-structured interviews with 34 sets of parents who had missed a General Paediatric outpatient appointment. "Domestic problems or other contingencies" were reported as the principal reason for non-attendance by 8 out of 34 parents and illness of the mother specified by a further three, reflecting the influence on attendance of unexpected occurrences in everyday social life.

Difficulties in accessing the appointments, including transport issues such as those reported in the observational studies above, were not cited as reasons for non-attendance in these two samples. However, parents in both studies reported that administrative errors played a part in non-attendance. In the research by Gatrad (1997), 7% of parents stated that they were not aware that an appointment would be scheduled, 5% had not received notification of an appointment, 5% could not

get through to the clinic to cancel the appointment and 5% had changed address. Change of address was also specified in the study by Andrews et al. (1990). Furthermore, both studies found that a high proportion of non-attenders cited forgetting the appointment as a principal reason for non-attendance (28% in Andrews et al., 1990; 13% in Gatrad, 1997). According to these findings, simple changes to administrative and communication procedures may significantly reduce non-attendance resulting from these factors, especially if an effective reminder system was implemented.

Parent-reported reasons for non-attendance also encompassed aspects related to their own attitudes and the health status of the child. Disagreeing with the need for the appointment and the parent's own fear of negative consequences of the appointment (such as finding out their child has a disabling condition, or being wrongly accused of child abuse) were cited reasons for missing an appointment in the study carried out by Andrews et al. (1990). The child no longer being ill was specified as a reason by 13% of parents in the Gatrad (1997) study and 31% of parents in the Andrews et al. (1990) study. Conversely, Gatrad (1997) also found that 7% of missed appointments were attributed to the child being too ill to come to hospital. This supports the findings of McClure et al. (1996) and Cooper and Lynch (1979) that non-attending children are not always less ill than those who attend their appointments.

Finally, two additional reasons for non-attendance were specified by parents in the studies by Gatrad (1997) and Andrews et al. (1990), which were not included in the correlational studies described above. Both reasons relate to the relationship between families and clinicians. Gatrad (1997) reported that 3% of non-attenders conveyed a poor relationship and low satisfaction with the healthcare professional during previous interaction. Parents in the second study asserted that the reason for the appointment had not always been made clear to them by the clinician (Andrews et al., 1990), contributing to their decision not to attend.

Neither of these two studies employed qualitative methods in the analysis of their conducted interviews; responses are presented in statistical form only. An in-depth understanding of the motivations behind parental decisions is therefore precluded. Nonetheless they provide some evidence that, in addition to individual circumstances and administrative issues, parents' views about the appointment, the clinician and their child's illness play an important role in whether or not a family will attend. Very little research has investigated attitudes and beliefs of parents in relation to attendance at paediatric outpatient appointments. It is crucial not to omit these factors when investigating non-attendance, as it will only be possible to design effective interventions if an accurate and comprehensive model of all relevant factors can be outlined. In addition to the investigations of routinely collected data and self-reported factual information of the type that have

already been carried out, studies implementing questionnaires of parental attitudes and beliefs should be conducted to look at the relationships between these constructs and attendance behaviour.

### **1.3.8 Summary of literature review**

In summary, the literature on factors associated with non-attendance and the reasons given by parents for missed appointments indicate numerous issues that could potentially be addressed to reduce the DNA rate at General Paediatric outpatient appointments. Several influencing factors could be managed by implementing practical changes. For example, improving access to the clinic for those who use public transport, perhaps by allocating appointments outside of peak travelling times; scheduling the minimum number of necessary appointments for individual families; reducing the waiting time to the appointment, where possible; improving patient-clinician communication; dealing with the causes of administrative errors; and implementing reminder systems. Evidence from previous studies also suggests that interventions might be targeted at specific cohorts of families, including those from more deprived areas; those with greater long-term social problems; families scheduled for follow-up appointments; families who have missed previous appointments and families of children with conditions that might be perceived as 'less serious', which may encompass many children referred to the General Paediatric service.

## **1.4 THEORETICAL PERSPECTIVE**

Attendance at children's hospital appointments has largely been investigated and explained through examination of socio-demographic and clinical variables, and their capacity to predict attendance and non-attendance. As highlighted in the section above, there have been some attempts to explore parents' reasons for non-attendance, but so far these studies have used only descriptive quantitative methods meaning that findings are 'thin' and do not sufficiently add to the understanding of psychological aspects of attendance behaviour. No studies in the area of paediatric medical secondary care have carried out in-depth qualitative or exploratory analysis of parents' reasoning, and no studies have tested the applicability of psychological or behavioural theories for understanding this behaviour. Some studies examining health beliefs in relation to engagement with different aspects of paediatric and adult healthcare have been conducted, for example in the areas of childhood immunizations and health screening programmes. However, these are not likely to yield findings that are sufficiently relevant to services primarily for diagnosis and treatment, rather than for preventive care.

One reason for this dearth of theoretical and psychological evidence regarding attendance in paediatric secondary care is that until now attendance has been perceived as an indicator of other concerns, rather than as a distinct behaviour with antecedents, correlates, and consequences. For example, attendance is used as a marker of clinic efficiency and accessibility to services. DNA rates tell service managers about cost-effectiveness, loss of revenue, clinic capacity, and equity of access to care. This is the first programme of study where attendance will instead be considered as a health behaviour recommended for optimising child health and non-attendance as a failure to perform this behaviour. This conceptualisation enables consideration of existing theories that outline the interaction of cognitive variables and behaviour, as well as the demographic and clinical factors identified in the literature review.

Given the paucity of existing psychological or behavioural research in this field, this thesis will include an inductive qualitative study wherein questions posed to interviewees reflect facets of the topic of interest, but are not drawn from theory or predetermined assumptions. The subsequent questionnaire study will derive theoretical constructs from the qualitative findings. It is not therefore necessary to identify specific psychological theories in order to proceed with this research. However, there are two overarching theoretical frameworks used for understanding health service use and concordance with healthcare recommendations that are useful for contextualising the research presented in this thesis.

First the 'Behavioural Model of Use of Health Services' proposed by Andersen (1995). The original version of this model was presented in the 1960s and has been updated by the original author to now include environmental factors (e.g. the healthcare system), different types of health behaviour (use of services and personal health practices), and outcomes (perceived health status, evaluated health status, and consumer satisfaction). Focusing on the original 'population characteristics' that refer to individual factors, Andersen (1995) proposes that there are predisposing characteristics, enabling resources, and health service need that all contribute to the use of health services. Predisposing characteristics include demographic variables, such as age and gender; social structure, including measures of employment, education and ethnicity; and health beliefs. Andersen defines health beliefs as, "attitudes, values and knowledge that people have about health and health services that might influence their subsequent perceptions of need and use of health services" (Andersen, 1995, p.2). The author explicitly notes that health beliefs are probably not sufficient, as the other factors 'enabling resources' and 'need' will continue to explain more of the variation in health service use. Enabling resources refer to personal, family and community factors that facilitate service use, such as having health facilities available where people live and work, having the means to get to

service locations, and influential social relationships. The construct of health service 'need' includes perceived need, or perceptions of health, functional state, symptoms and worries about illness, as well as evaluated need, which represents the healthcare professional's judgement about health status and need for medical care. This model provides a useful framework for considering the various levels of factors that may interact to predict use of paediatric secondary care services, and many of the variables discussed in the literature review section would be encompassed by this model.

A second useful theoretical framework to consider is that of intentional and unintentional non-adherence, which is described as a "model for guiding interventions" (Morgan & Horne, 2005). This model was developed to explain non-adherence to prescribed medicines, and to show the conceptual distinction between non-adherence that occurs erroneously and non-adherence that is based on deliberate choice. Lehane & McCarthy (2007) define intentional non-adherence as "undertaking an active, reasoned decision-making process in relation to following or disregarding professional advice" (p.1469). Within intentional non-adherence, social cognition models can be applied, which describe the cognitive processes underpinning 'social' health behaviour.

Unintentional non-adherence on the other hand is assumed to be the result of a passive process, and is less strongly associated with cognitions than intentional non-adherence, though not entirely unrelated. Unintentional factors include patient variables such as age, knowledge, and forgetfulness; treatment variables such as number of medicines prescribed and medicinal side-effects; and patient-provider variables, such as quality of relationship with healthcare professionals (Lehane & McCarthy, 2007).

This framework has not yet been applied to behaviours other than medicine-taking in published studies, but considering that 'forgetting' is an oft cited reason for non-attendance, it is reasonable to assume that both aspects of this model are likely to play a role in missed outpatient appointments. Together these two theoretical frameworks provide an overarching structure and foundation for understanding the possible psychological factors associated with non-attendance at paediatric hospital appointments.

### **1.5 ORIGIN OF THE PROJECT**

This project is part of a wider programme of research funded by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) programme for Birmingham and Black Country. One section of this programme, the 'Evaluation of paediatric outreach services', is a collaborative venture between researchers at the University of Birmingham and Aston University, and clinicians and executive staff at Birmingham Children's



Hospital NHS Foundation Trust. The aim of this partnership is to carry out applied health research addressing issues identified by the hospital, and to facilitate the transfer of academic research findings into National Health Service (NHS) practice. Clinical members of this partnership have previously identified non-attendance at General Paediatric outpatient clinics as an area of concern and a priority topic for research (Cummins et al., 2009). The premise and design of this PhD project has consequently been developed in close collaboration with the General Paediatric service at BCH.

## **1.6 RATIONALE AND OUTLINE OF THE THESIS**

The above sections have demonstrated that non-attendance at paediatric outpatient appointments is a prevalent and serious problem at Birmingham Children's Hospital as well as nationally and internationally. Research to date has focused on demographic and clinical factors, and has been lacking in theoretical foundations. The objective of this project is to consider the current management of missed appointments and to conduct an in-depth exploration of the psychological factors associated with non-attendance at General Paediatric outpatient clinics. One systematic literature review and three empirical studies are presented, using a pragmatic mixed methods approach and various research methods. The structure of the thesis is as follows:

- First, a brief overview is provided of the methodology used in this thesis and a justification for the research design
- A systematic review is presented which aims to demonstrate the effectiveness, theoretical foundations and behaviour-change techniques utilised in existing interventions intended to reduce non-attendance at General Paediatric appointments
- The first empirical chapter is a qualitative study employing semi-structured interviews and a thematic framework analysis to examine the beliefs of healthcare professionals and other healthcare decision-makers about the reasons for non-attendance in General Paediatric clinics, and what strategies ought to be implemented to overcome this problem
- Next, a qualitative study of parents' views and experiences of attending and missing General Paediatric appointments provided by Birmingham Children's Hospital. This study also uses semi-structured interviews and a thematic framework analysis to answer the question, 'What are the beliefs or cognitive factors that influence attendance at General Paediatric outpatient appointments?'
- The third study is a quantitative, cross-sectional investigation of parents' beliefs about attendance and non-attendance, using postal survey methods and an exploratory factor analysis to investigate the latent psychological factors underlying parental cognitions about attending appointments

- The final chapter provides a summary and discussion of the findings of the thesis, including links to literature, implications for theory and clinical practice, and considerations of the strengths and limitations of the research.

## CHAPTER TWO

### 2. Methodology

#### 2.1 INTRODUCTION

This chapter describes the methodological approach taken to achieve the research aims outlined in chapter one. This includes a justification of the decision to use a mixed methods research approach, an explanation of the philosophical pragmatist assumptions underpinning this approach, and an overview of the specific mixed methods design.

#### 2.2 JUSTIFICATION FOR A MIXED METHODS APPROACH

The overarching aims of this doctoral research are to consider existing interventions and management strategies for reducing missed appointments at General Paediatric outpatient clinics, and to elucidate the psychological factors associated with attendance and non-attendance. In order to best meet these objectives, both qualitative and quantitative approaches are necessary.

Very little prior work has been conducted which addresses parental cognitions in this context. There are therefore no well-established theories or proposed psychological constructs of importance. Consequently, an inductive qualitative approach is necessary to obtain a rich understanding of parents' beliefs and experiences in this particular research area. Yet, in order to move from a set of identified individual cognitions to understanding how these cognitions are related in terms of underlying psychological structure, it is also necessary to conduct quantitative analyses. A quantitative approach also permits testing of the existence of the identified cognitions in a larger sample so that inferences can be drawn about psychological factors in the parental General Paediatric population, and to outline a factor structure that can be used in future research as the basis of a reliable questionnaire measure and of a theoretical model for understanding parental attendance behaviour. Neither approach would be sufficient on its own. The quantitative phase requires a preceding qualitative phase in order to identify which variables to measure, and the underpinning psychological factor structure could not be obtained through purely qualitative methods as the underlying 'latent' variables are not accessible through direct means, and participants may be largely unaware of them. A dual approach is therefore necessary.

However, there has been much controversy and debate about whether it is appropriate to combine qualitative and quantitative approaches, as they represent alternative research 'paradigms'. A paradigm is a "worldview, complete with the assumptions that are associated with that view" (Mertens, 2003, p.139), meaning the belief structure within which the research is conducted and the

related philosophical principles. These associated assumptions include theory on the nature of reality (ontology), the justification of knowledge (epistemology), and how knowledge is constructed (methodology) (Tebes, 2005).

Quantitative research is said to be aligned with a 'scientific' or positivist viewpoint, and is characterized by empirical research. The ontological position of this paradigm is that there is an objective reality that exists independently of human perception, and that there is only this one 'truth'. In epistemological terms, the researcher and the object of the research are thought to be independent entities, and it is possible for the researcher to study the object of inquiry without influencing it or being influenced (Sale et al., 2002). Methods used within quantitative research include highly structured procedures and questionnaires with predetermined response categories.

In contrast, qualitative research is an interpretive or constructivist paradigm (Yardley & Bishop, 2008). The ontology within this paradigm is based on the assumption that there are multiple truths and multiple realities, and that reality is socially constructed. Epistemologically, reality cannot be accessed independently of the human mind and the researcher and the object of the research interact to create mutual findings related to the context within which the research takes place (Sale et al., 2002). Methods include interviews, observations and analyses that focus on meanings and experiences.

The two paradigms differ fundamentally in terms of ontology and epistemology, and have had different histories shaping their development. They therefore also differ in terms of the type of logic invoked (i.e. deductive versus inductive), the purpose of the research (i.e. confirmatory versus exploratory), the types of research question that can appropriately be addressed, the types of data sought (i.e. numeric versus narrative), the ways in which participants are sampled (i.e. probability versus purposive sampling), and the methods of data analysis (i.e. statistical versus thematic) (Teddle & Tashakkori, 2009).

Given the very different assumptions attributed to each paradigm, it has been claimed that quantitative and qualitative approaches are 'incompatible' and should not be combined (Howe, 1988). Guba (1987) stated that, "The one [paradigm] precludes the other just as surely as belief in a round world precludes belief in a flat one" (p.31). This proposed incompatibility extends to research methods as well as paradigm assumptions, as supporters of this argument see methods as irrevocably tied to one paradigm (Teddle & Tashakkori, 2009). However, others have argued that the two approaches can be used in combination and that there is as much diversity within the paradigms as there is between them (Hammersley, 1996). Some authors have argued that qualitative and

quantitative approaches are part of a continuum of research, with methods selected based on the research question (Casebeer & Verhoef, 1997).

### **2.3 THE CASE FOR PRAGMATISM**

Proponents of a mixed methodology approach point out that the two paradigms that have dominated research in the past, qualitative and quantitative, may not be the only two paradigms and that another philosophy of inquiry, pragmatism, can be adopted to reject the forced choice between the former approaches (Howe, 1988). Pragmatism as a philosophical movement was born out of the work of 19<sup>th</sup> century philosopher Charles Sanders Peirce, and developed by William James, John Dewey, George Herbert Mead and Arthur F. Bentley (Maxcy, 2003). Pragmatists point out that, “all human inquiry involves imagination and interpretation, intentions and values, but must also necessarily be grounded in empirical, embodied experience” (Yardley & Bishop, 2008, p.355). From a pragmatist perspective, practical consequences are thought to be essential parts of meaning and truth, such that theories are ‘true’ to the extent that they ‘work’ in terms of applicability and feasibility (Dures et al., 2010).

A combination of the pragmatist paradigm and a mixed methods approach mean that researchers can choose the methods and techniques that best suit the needs and purposes of their study. Data generated from traditionally qualitative and quantitative methods can be combined because together they offer the best way to understand the research topic (Cresswell, 2003). Yet, Yardley and Bishop (2008) point out that the two very different kinds of research must be combined in ways that do not compromise their integrity. Greene et al. (1989) present five justifications for combining quantitative and qualitative research: triangulation (to corroborate results from different methods); complementarity (to elaborate, enhance or clarify results from one method with the results of another); development (using the results from one method to develop the other method, e.g. in terms of sampling or measures); initiation (to seek contradictions and new perspectives by contrasting results from one method with another); and expansion (to extend the range of inquiry by using different methods for different parts of the research).

The justification for employing mixed methods in this thesis is represented by the second of these aims, complementarity. Sale et al. (2002) advocates the combination of quantitative and qualitative methods for ‘complementary purposes’ and notes that, “Each method studies different phenomena” (p.50), meaning that while the construct of interest is the same, different methods focus on different aspects of the construct. The example given is that of measuring nurses’ experience of ‘burnout’; qualitative methods would address the lived experience of the phenomenon, while quantitative

methods would inform a measure of the construct. Similarly, in this project the qualitative methods are designed to obtain an in-depth, rich understanding of parents' and healthcare professionals' views, beliefs and experiences of attended and missed appointments, while the quantitative methods are intended to measure the distribution of beliefs in a larger sample of parents and test the relationships between the measured beliefs to elucidate an underlying structure. This demonstrates one of the central principles of mixed methods research, that the use of both qualitative and quantitative methods in combination provides a better understanding of the phenomenon under study than using either approach alone (Cresswell & Plano Clark, 2007, p.5).

#### **2.4 THE MIXED METHODS RESEARCH DESIGN**

Cresswell and Plano Clark (2011) provide a list of key components that define mixed methods research, including: rigorous analysis of both types of data, based on the research questions; mixing two forms of data concurrently or sequentially; giving priority to one or both types of data; and using mixed methods procedures either in a single study or in multiple phases of a programme of study (p.5). In this project an exploratory sequential design will be implemented, consisting of three phases. First, a minor qualitative phase on which less emphasis will be placed, followed by the major qualitative phase and subsequent quantitative phase which will be equally weighted. This can be represented with the standard mixed methods notation developed by Morse (2003, p.198) as:

qual → QUAL → QUAN.

The first 'qual' phase consists of data collection via semi-structured interviews with healthcare professionals and other NHS decision-makers, data analysis using a thematic framework approach, and presentation of findings in the form of themes. This data will have less importance for answering the main research question regarding parental cognitions and psychological factors, as clinicians can only provide proxy information about parents' experiences. Though, the findings may provide supplementary information about the experience of attending appointments that is not addressed in the later QUAL phase. The main intention of this phase is to consider the views of clinicians and how these views influence the ways in which they manage non-attendance. This addresses the secondary research aim of assessing existing and proposed interventions and management strategies.

The main QUAL phase employs the same procedures as the preceding qualitative phase, but this time with parents of General Paediatric patients. The findings of this phase will inform the variables to be measured in the subsequent quantitative stage. The QUAN phase involves data collection via questionnaire and postal survey methods, data analysis using descriptive statistics and exploratory

factor analysis, and presentation of findings in the form of an underlying factor structure. Details of the specific methods use in each phase are provided in each of the empirical chapters.

## **2.5 SUMMARY OF METHODOLOGY**

Employing pragmatist assumptions and a mixed methods research design, this thesis will explore current 'did-not-attend' management strategies and parental psychological factors related to non-attendance at General Paediatric outpatient clinics in three empirical studies. The findings from these qualitative and quantitative studies will be supplemented by a systematic literature review of existing non-attendance interventions. The evidence from this review and the empirical studies will be considered separately in each of the following chapters, then compared and synthesised in the discussion chapter to develop a new understanding of the factors underlying non-attendance and recommendations for managing missed appointments.

## CHAPTER THREE

### 3. Systematic review of interventions to reduce non-attendance

#### 3.1 INTRODUCTION

The ultimate aim of this thesis is to report the psychological factors related to paediatric non-attendance and to make recommendations for interventions based on these findings. However, it is first necessary to examine the ways in which missed appointments have been managed thus far, and whether existing approaches have been successful in reducing 'did-not-attends'. Additionally, by evaluating the theoretical foundations and incorporated behaviour change techniques of prior interventions it will be possible to assess whether parental cognitions have yet been targeted. Consequently, this chapter reports the methods and findings of a systematic literature review of the effectiveness, theoretical foundations, and behaviour change techniques of existing interventions intended to reduce non-attendance at General Paediatric outpatient clinics.

##### 3.1.1 Interventions to reduce non-attendance

Several types of intervention have been previously implemented or suggested for decreasing the number of missed appointments in various health services, including primary and secondary care clinics for adults and children. Strategies include providing incentives or rewards for attending (Finney et al., 1990; Giuffrida & Torgerson, 1997); administering fines or penalties for non-attendance (Bech, 2005; Roberts et al., 2011); contracting with patients (Hayes et al., 2000); asking patients to confirm attendance prior to the appointment (Cohen et al., 1980); sending patients copies of the referral letter (Hamilton et al., 1999); increasing choice and flexibility of appointments (Modayil et al. 2009); improving access, removing barriers, or reducing effort to attend (Friman et al., 1985); and culturally sensitive strategies, such as taking religious holidays or customs into account (Gatrad, 2000).

However, the intervention that has received the most attention in published research and appears to be most commonly implemented is provision of appointment reminders. Studies have evaluated the delivery of reminders by post (e.g. Morse et al., 1981; Campbell et al., 1994), telephone (e.g. Ritchie et al., 2000; Reti, 2003; Roberts et al., 2007), email (e.g. Atherton et al., 2012) and text message (e.g. Milne et al., 2006; Foley & O'Neill, 2009) in a variety of settings. There is specific evidence to suggest that the use of reminders in General Paediatric services is effective in reducing non-attendance at appointments (Shepard & Moseley, 1976; Quattlebaum, 1991; O'Brien & Lazebnik, 1998; Downer et al., 2005; Kofoed, 2009; Downer et al., 2011) and can be used successfully in combination with other



strategies, such as reducing effort to attend by providing a parking pass (Friman et al., 1985; Ross et al., 1993).

Many systematic reviews have been conducted on the effectiveness of different types of appointment reminders across all health settings (Henderson, 2008; Hasvold & Wootton, 2011; Atherton et al., 2012; Car et al., 2012; Guy et al., 2012; Stubbs et al., 2012). However, only one systematic review has evaluated all interventions for improving attendance at appointments, and this paper is now likely to need updating as mobile phones and email systems have since been introduced (Macharia et al., 1992). There are also several reviews considering the effects of different interventions on adherence with medical regimens, which includes appointment keeping (e.g. Roter et al., 1998; Van Dulmen et al., 2007), and one specifically addressing the use of financial incentives for increasing patient compliance (Giuffrida & Torgerson, 1997). However, the factors associated with adherence to medication may be quite different to those related to attendance at appointments, so it may be more appropriate and useful to evaluate effects on appointment keeping separately.

Additionally, very few authors have considered attendance interventions specifically in paediatric settings. One review was conducted by Cincinnati Children's Hospital Medical Center (2012) investigating the effects of electronic reminders on medication adherence and outpatient appointment keeping in paediatric patients and families. However, insufficient detail on search methodology, quality appraisal, study findings and evidence synthesis was provided in the published report. Another systematic review by Benway et al. (2003) evaluated interventions to increase initial appointment attendance at child and family mental health clinics. However the factors related to attendance at such sub-specialty services, and the perceptions and experiences of families referred to those services, are likely to be substantially different to those of families attending children's general medical appointments, thus requiring quite different interventions. It is therefore necessary to consider the issue of non-attendance separately for paediatric sub-specialty clinics, such as psychiatry, surgery and oncology, as well as dental and primary care services. No prior review has considered attendance interventions in General Paediatric outpatient appointments. Thus to provide an adequate evidence base and to report which approaches have been effective, it is necessary to supplement the existing literature by carrying out a systematic review of all published interventions to reduce non-attendance at General Paediatric outpatient services.

### **3.1.2 Theoretical foundations of interventions**

Attendance at hospital appointments is a health behaviour carried out by individual patients and families, with associated antecedents and consequences of behaviour. However it has received little attention in terms of behavioural theory compared to, for example, medication adherence, uptake of immunizations, or attendance at screening appointments. Outpatient appointment attendance has more often been considered within the field health service management, as an indicator for outcomes such as efficiency, clinic utilisation, or access to services. Yet social and psychological theories of behaviour could readily be applied to attendance at appointments and used for designing non-attendance interventions. Indeed, it has been recommended that interventions should be theory-based as well as derived from appropriate evidence, in order to be most effective (Michie & Abraham, 2004; Michie et al., 2005). It is therefore necessary to consider the theoretical underpinnings (or lack thereof) of interventions so that useful theories and theoretical constructs can be recommended, in addition to intervention methods.

However, as a result of this inattention to behavioural theory, non-attendance interventions tend to be based solely on pragmatic choices about particular service resources and local clinicians' or managers' perceptions of the reasons for non-attendance, which may not match those given by patients and families (e.g. Zeber et al., 2009). It is therefore expected that few articles in this review will report use of theory or theoretical constructs in designing interventions. This may preclude conclusions about the effectiveness of different theories, but would nonetheless be a useful finding in demonstrating the extent of lack of theory in designing interventions in paediatric outpatient settings.

It has also been recommended that reports of interventions should provide more explicit detail on the precise techniques used to change behaviour, so that studies can be replicated and conclusions can be drawn about the specific methods associated with success or failure of interventions (Michie et al., 2009). A taxonomy of behaviour change techniques (BCTs) has been developed (Abraham & Michie, 2008; Michie et al., 2013) so that a common language can be used to describe intervention methods, allowing comparisons of the effectiveness of particular BCTs to be made across intervention studies. Therefore, in addition to evaluating effectiveness and theoretical underpinnings, this systematic review will also consider the behaviour change techniques incorporated in interventions to reduce non-attendance in paediatric outpatient settings.

### **3.1.3 Review questions**

How effective are interventions that aim to reduce non-attendance at General Paediatric outpatient appointments?

Which theoretical models and behaviour-change techniques have been used in the design and implementation of these interventions?

### **3.1.4 Objectives**

- To identify the range and types of existing interventions
- To evaluate the effectiveness of these interventions in reducing non-attendance rates
- To assess the use of theory in the development of interventions
- To document the specific behaviour-change techniques used in interventions

## **3.2 METHODS**

### **3.2.1 Criteria for considering studies for the review**

#### Types of studies

This review considered primary research studies that reported quantitative evaluations of at least one intervention, using parallel group comparison or adequate before-after designs. Acceptable designs included randomised-control trials (RCTs), non-randomised control trials (NRCTs), controlled before-after studies (CBAs), cohort studies, interrupted time series (ITS) studies, repeated measures studies, and before-after studies. Cross-sectional studies, qualitative reports, case studies, case series and literature reviews were not included, but reference lists of highly relevant papers were checked for relevant articles.

#### Participants

The population of interest was children and young people, or their parents and caregivers. Studies conducted on mixed child and adult samples were only considered if data on children or adolescents were reported separately. Studies with wholly adult samples were excluded.

#### Settings

The review targeted studies of attendance at General Paediatric outpatient services, meaning appointments provided by secondary care or hospital clinicians specialising in children's general medicine. This could have included, but was not limited to, patients referred to a paediatrician for

assessment, diagnosis, tests, treatment, or review. The act of referral was considered important as clinics that could be accessed directly by families would very likely be treated differently to those where access was negotiated through a 'first contact' provider. Therefore studies of direct access or primary care services, whether provided by family doctors or paediatricians (including preventive or well-child visits, screening, and routine immunizations) were excluded.

Studies conducted wholly in paediatric medical sub-specialties, such as cardiology, oncology, dermatology, respiratory, ophthalmology, or endocrinology services were not included. Studies of numerous services were only considered if data regarding General Paediatric medicine was reported separately. Inclusion of articles in the review was not limited by type of clinician providing the appointments or by location of the service. Clinics delivered by nurses or other healthcare professionals, or in locations other than a hospital setting were considered as long as other inclusion criteria were met.

### Interventions

Research on any interventions designed specifically to influence attendance rates at children's outpatient appointments were considered for review.

### Outcome measures

The primary outcome measure to be evaluated was attendance at appointments. Other outcome measures, such as families' evaluations of the intervention, were recorded if present.

### Other criteria

There was no limit on the earliest year of publication for studies included in the review, as results from older studies of healthcare services could still provide relevant and useful findings for present day interventions. Furthermore the selection of a year by which to limit the review would have been arbitrary and would have unnecessarily limited the pool of potential studies, which was already likely to be small. The review was however limited to studies where the full report was available in English. This was due to the time and resource constraints of the review.

## **3.2.2 Search methods for identifying studies**

### Sources for identifying studies

The following electronic databases were searched from the earliest year available:

- The Cochrane Library Central Register of Controlled Trials (CENTRAL; via Cochrane Library)

- Health Technology Assessment Database (HTA; via Cochrane Library)
- NHS Economic Evaluation Database (EED; via Cochrane Library)
- MEDLINE (including in-process and other non-indexed citations; via Ovid SP)
- Embase (via Ovid SP)
- PsycINFO (via Ovid SP)
- Healthcare Management Information Consortium (HMIC; via Ovid SP)
- CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature; via EBSCO)
- Science Citation Index Expanded (via Web of Science in Web Of Knowledge)
- Social Sciences Citation Index (via Web of Science in Web Of Knowledge)

Relevant grey literature was checked by searching the ProQuest Dissertations and Theses database and the Conference Proceedings Citation Indices for Science, and for Social Science and Humanities, available through Web of Science in Web of Knowledge. Additional studies were identified by checking the reference lists and citations of included studies and key articles for relevant titles.

#### Search strategy for electronic databases

The search strategy presented in figure 1 was developed for use in MEDLINE (via Ovid SP), and was adapted for use with the other databases. For example, different index headings such as Medical Subject Headings (MeSH terms) and search operators were employed for different searches.

### **3.2.3 Data collection and analysis**

#### Selection of studies

Duplicate articles, where the same paper or citation had been returned by more than one database, were discarded prior to reviewing titles and abstracts for inclusion. The review author then evaluated the relevance of all citations identified through the electronic searches. Full text copies were obtained of studies thought to be potentially relevant at this stage. The reference lists and citations of key papers were checked for additional articles then all identified papers were assessed against the criteria described above for inclusion in the review. Where fulfilment of the inclusion criteria was uncertain, the review author discussed the article with a supervisor (Dr Carole Cummins) and a decision was made in collaboration.

#### Data extraction and management

Each full text article was checked for exclusionary characteristics. Reasons for non-inclusion were provided if studies were not selected for review, and all decisions were discussed and confirmed with

**Figure 1. Example of search strategy for electronic database searching**

<b>MEDLINE search strategy</b>
1. Appointments and schedules/ <sup>a</sup>
2. appointment\$ <sup>b</sup>
3. 1 or 2
4. Ambulatory care/
5. Ambulatory care facilities/
6. Outpatient clinics, hospital/
7. Outpatients/
8. outpatient\$ or out-patient\$
9. 4 or 5 or 6 or 7 or 8
10. Pediatrics/
11. p\$ediatric\$
12. child\$ OR adolescen\$ OR teen\$ OR infant\$
13. 10 or 11 or 12
14. Patient compliance/
15. Patient acceptance of health care/
16. attend\$ or non-attend\$ or nonattend\$ or no-show\$ or noshow\$ or "broken appointment\$" or "fail\$ appointment\$" or "miss\$ appointment" or "fail\$ to attend" or default\$ or dropout\$ or drop-out\$ or "did not attend" or "was not brought" or "compl\$ with appointment\$" or "appointment compliance" or "appointment keep\$" or appointment-keep\$
17. 14 or 15 or 16
18. 3 and 9 and 13 and 17

<sup>a</sup> Forward slash (/) denotes a MeSH term

<sup>b</sup> Dollar sign (\$) denotes use of a wildcard to search for alternative spellings and plural endings

a second reviewer (Dr Carole Cummins). Data was extracted from included articles using an adapted template provided by the Cochrane Effective Practice and Organisation of Care (EPOC) group (see appendix 3.1) and associated guidance. Extracted data included: general information about the authors and paper; study population and setting; study design and methods; risk of bias; participants; intervention; use of theory; use of behaviour change techniques; outcomes; and results.

Risk of bias assessments for adequately controlled studies (i.e. RCTs, NRCTs, CBAs, ITS) were carried out according to EPOC group guidance (Cochrane Effective Practice and Organisation of Care Group, 2013). EPOC did not provide sufficient guidance for assessing the quality of observational studies so a separate Critical Appraisal Skills Programme (CASP) tool was used to evaluate risk of bias in all other studies (Critical Appraisal Skills Programme, 2013). Collecting information on the use of theory and

coding of behaviour-change techniques was carried out following the guidelines published by Michie & Prestwich (2010) and Michie et al. (2013). A narrative synthesis of the studies was then conducted with summaries in tables of extracted data, and results reported following PRISMA guidelines (Moher et al., 2009; Liberati et al., 2009).

### **3.3 RESULTS**

#### **3.3.1 Results of the search**

Database searches returned 1692 articles and a further 47 papers were identified by hand searching the references and citations of relevant papers. After 583 duplicate records were removed the titles and abstracts of 1156 articles were screened. At this stage 1102 papers were excluded due to insufficient relevance to the review topic, 6 articles were unobtainable in full text within the time constraints of the review, and 3 were unavailable as full articles in English. Full text copies of the remaining 45 papers were obtained and checked against the inclusion criteria, and a further 37 articles were subsequently excluded. Twelve of these did not report the findings of an intervention study or were unrelated to paediatric health care. The other 25 papers reporting 24 studies initially appeared suitable for review, but did not meet all inclusion criteria. Many of these were conducted in the USA where paediatric outpatient clinics often incorporated direct access or primary care elements and so were not appropriate for this review. Reasons and evidence for excluding these 25 articles are provided in table 1. Eight papers met all of the stipulated criteria and were included in the review. One of these was a conference abstract (McMillan & Jayatunga, 2012) while the other seven were full journal articles. A PRISMA flowchart (Moher et al., 2009) of this paper selection process is presented in figure 2.

#### **3.3.2 Description of included studies**

Key characteristics of the eight included studies are described below and presented in table 2.

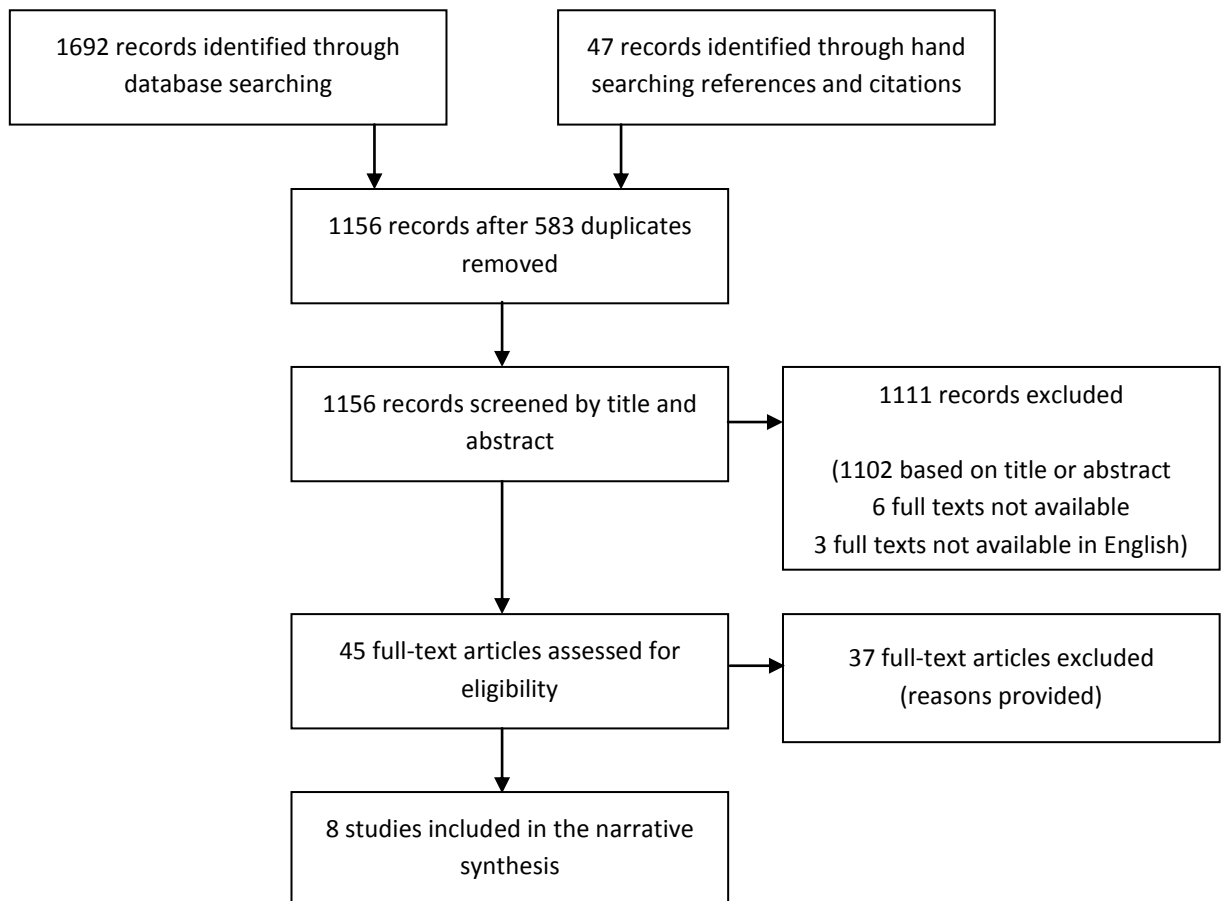
##### **3.3.2.1 Settings and participants**

Three studies were conducted in the UK (Gatrad, 2000; McMillan & Jayatunga, 2012; Milne et al., 2006), two in Australia (Downer et al., 2005; Sawyer et al., 2002), and one each in Saudi Arabia (Altuwaijri et al., 2012), Switzerland (Chariatte et al., 2007) and the USA (Komoroski et al., 1996). Four were carried out in children's hospitals: three in general medical clinics (Downer et al., 2005; Komoroski et al., 1996; Milne et al., 2006) and one in an adolescent health clinic (Sawyer et al., 2002).

**Table 1. Papers excluded from the review**

<b>Study</b>	<b>Country</b>	<b>Reason for exclusion</b>	<b>Evidence supporting exclusion</b>
Beach 1990	USA	Not secondary care	A “ <i>public clinic</i> ”. Likely to include primary care or direct access based on similar excluded studies in USA clinic settings and information about this health organization available online.
Becker 1974	USA	Not secondary care	A “ <i>children and youth project</i> ” for low income families “ <i>experiencing discontinuous care</i> ” with primary medical services
Casey 1985	USA	Not secondary care	“ <i>Walk-in clinic</i> ” at a children’s hospital
Danoff 1993	USA	Not secondary care	Same clinic as Levy 1977
Downer 2006	Australia	General Paediatrics not reported separately	Included “ <i>all patients</i> ” with an outpatient appointment at a children’s hospital
Fink 1969a	USA	Not secondary care	“ <i>Acute care clinic</i> ” (minor illnesses and injuries)
Fink 1969b	USA	Not secondary care	Same as above - duplicate report of findings presented in Fink 1969a
Fink 1969c	USA	Not secondary care	Same clinic as Fink 1969a and Fink 1969b
Friman 1985	USA	Not secondary care	Included “ <i>child health supervision</i> ” (i.e. primary care)
Friman 1987	USA	Not secondary care	Included “ <i>well child care</i> ” (i.e. primary care)
Gerson 1986	USA	Not secondary care	Included “ <i>preventive services</i> ” (i.e. primary care)
Hackett 2008	USA	Not General Paediatrics	A “ <i>medical/behavioural</i> ” clinic providing treatment to children with “ <i>developmental, behavioural or emotional problems</i> ”
Jamil 2011	Malaysia	General Paediatrics not reported separately	“ <i>Involved all the sub-specialist and general paediatric clinics</i> ”
Kavanagh 1989	USA	Not General Paediatrics; not secondary care	“ <i>Indigent pediatric otology clinic</i> ” with many visits for “ <i>newborn auditory screening</i> ”
Kavanagh 1990	USA	Not secondary care	“ <i>Healthcare facility</i> ” administered by county “ <i>Health Department</i> ”
Kelsall 2005	UK	Not General Paediatrics	“ <i>General paediatric cardiac</i> ” and other paediatric cardiac clinics
Levy 1977	USA	Not secondary care	Included “ <i>well-child visits</i> ” (i.e. primary care)
Milne 2010	UK	General Paediatrics not reported separately	“ <i>Consultant-led outpatient appointments... Twenty-five major specialties are covered.</i> ”
Narring 2013	Switzerland	Not secondary care	“ <i>Primary care youth clinic</i> ” at a university hospital
Nazarian 1974	USA	Not secondary care	“ <i>Multi-specialty health facility</i> ” serving a low-income area; “ <i>health center population</i> ”
O’Brien 1998	USA	Not secondary care	“ <i>Routine medical and preventive care at the adolescent clinic</i> ”
Quattlebaum 1991	USA	Not secondary care	“ <i>A primary care practice</i> ”
Ross 1993	USA	Not secondary care	Included “ <i>well-child health care</i> ”
Shepard 1976	USA	General Paediatrics not reported separately	“ <i>General Eye and ENT clinics</i> ” and “ <i>patients seen previously in the Emergency Room</i> ”
Wingert 1975	USA	General Paediatrics not reported separately	“ <i>Scheduled appointments at their respective specialty clinics</i> ”





**Figure 2. PRISMA flowchart of paper selection process**

The other four were carried out at general or university hospitals, again with three in General Paediatric clinics (Altuwaijri et al., 2012; Gatrad, 2000; McMillan, 2012) and one in an adolescent clinic (Chariatte et al., 2007). All of the studies evaluated the attendance of patients scheduled to visit outpatient clinics, though in the trial by Komoroski (1996) participants were initially identified and recruited in the same hospital's emergency department.

All studies included male and female patients, though gender distribution was described in only three papers. Komoroski et al. (1996) and Sawyer et al. (2002) reported 54.7% and 49.3% male participants respectively, though Chariatte et al. (2007) reported just 17.6% male patients in their total data set. Chariatte et al. (2007) and Sawyer et al. (2002) conducted research in adolescent clinics for 12-20 and 12-19 year-old patients. No ages were described in any other articles, though all clinics were explicitly for paediatric patients (typically under 16 or 18 years of age). Ethnicity was reported in two studies. Gatrad (2000) specifically investigated the differences in intervention effects between Asian and European families and indicated that Asian patients constituted 16.4% of their

intervention cohort and the remainder were European. Komoroski et al. (1996) observed that 43% of their participants were white and 54.7% black (the remaining 2.3% was not reported).

All but two studies included all scheduled appointments, implying both new and follow-up visits though this was only made explicit in one paper (Chariatte et al., 2007). The ratio of new to review appointments was described by Milne et al. (2006) who specifically investigated new and follow-up appointments as distinct sub-groups (23.7% new appointments out of total sample), and by Sawyer et al. (2002) who noted an average of 26.7% new appointments. The study by McMillan & Jayatunga (2012) included only follow-up appointments and Komoroski et al. (1996) included only new appointments due to the nature of recruitment for these two studies.

### **3.3.2.2 Research designs**

Two studies were randomised control trials, one in which the unit of randomisation was the family (Komoroski et al., 1996) and one in which randomisation was applied at the level of the clinic such that each week patients scheduled to attend two out of four randomly selected clinics received the intervention while those attending the other two clinics did not (Sawyer et al., 2002). Komoroski et al. (1996) compared a standard intervention group and intense intervention group to current procedure, in which no appointment was scheduled but families were asked to telephone the hospital to make follow-up arrangements.

One study used a cohort design with comparison of the intervention group to a usual practice non-intervention group, and additionally compared the effect of the intervention in new appointments using a partial booking system against follow-up appointments with no partial booking (Milne et al., 2006). The remaining five studies implemented a cohort design with historical control, meaning a retrospective comparison to the non-attendance rate in a specified period before the introduction of the intervention (Altuwajiri et al., 2012; Chariatte et al., 2007; Downer et al., 2005; Gatrad, 2000; McMillan & Jayatunga, 2012).

The eight studies ranged in size from 171 families to 33,388 booked appointments. Trials investigated the attendance of particular recruited families, while cohort studies examined all scheduled appointments within the specified time periods, which could include return visits by the same patients. The time periods examined and compared in the cohort studies with historical controls were one month (Downer et al., 2005), three months (Altuwajiri et al., 2012), eight months (McMillan & Jayatunga, 2012), one year (Gatrad, 2000), and in the case of Chariatte et al. (2007) five years pre-intervention and three years post-intervention. Milne et al. (2006) assessed non-attendance rates in a two-month period, Sawyer et al. (2002) conducted their trial over six months,

**Table 2. Papers selected for inclusion in the review**

Study ID	Country	Setting	Intervention	Study design	Outcome measure	Study size	Control DNA rate	Intervention DNA rate
Altuwaijri 2012	Saudi Arabia	Medical paediatric outpatient clinic	SMS text reminders	Cohort study with historical control	Non-attendance rate	33,388 appointments Control: 17,111 Intervention: 16,277	3988 <b>(23.3%)</b>	3090 <b>(18.9%)</b> ( $\chi^2=93.05$ , $p<.0001$ ) (Review author's calculation)
Chariatte 2007	Switzerland	Adolescent multidisciplinary hospital outpatient clinic	Hospital policy, paying for appointments not cancelled in advance	Cohort study with historical control	Missed appointment rate	32,816 appointments Control: 19,263 Intervention: 13,553	2292 <b>(11.9%)</b>	1572 <b>(11.6%)</b> (Adjusted odds ratio (AOR) 0.96, 99% C.I. 0.83-1.10)
Downer 2005	Australia	General medicine outpatient clinic at a children's hospital	SMS text reminders	Cohort study with historical control	Failure to attend rate	1248 appointments Control: 669 Intervention: 579	141 <b>(21%)</b>	88 <b>(15%)</b> ( $\chi^2=6.77$ , $p=.0093$ ) (Review author's calculation)
Gatrad 2000	UK	Paediatric hospital outpatient department	Multi-faceted intervention including improved communication, cultural awareness and reminders	Cohort study with historical control	Non-attendance rate	13,581 appointments  <u>Control:</u> 4482* Asian: 643, European: 3839  <u>Intervention:</u> 9099 Asian: 1496 European: 7603  *(Data obtained from Gatrad, 1997)	1574 <b>(35%)*</b>  Asian: 320 (49.8%)* European: 1254 (32.7%)*  *(Data obtained from Gatrad, 1997)	1118 <b>(12.3%)</b> ( $\chi^2=983.46$ , $p<.0001$ ) (Review author's calculation)  Asian: 202 (13.5%) European: 916 (12%)

Study ID	Country	Setting	Intervention	Study design	Outcome measure	Study size	Control DNA rate	Intervention DNA rate
Komoroski 1996	USA	Emergency department (ED) and outpatient clinics at a children's hospital	<u>Intervention 1:</u> Appointment time & written reminder given pre-discharge from ED <u>Intervention 2:</u> Appointment time & written reminder pre-discharge; work, child care and travel assistance; mailed & telephone reminders	Randomised control trial	Follow-up compliance rate	253 families  Control: 89 Intervention 1: 85 Intervention 2: 79	68 ( <b>76%</b> ) <i>(Converted from the 'kept' follow-up rate)</i> <i>(Appointments were not scheduled for control families; parents were asked to call to make an appointment)</i>	Intervention 1: 45 ( <b>53%</b> ) (p<.001)  Intervention 2: 38 ( <b>48%</b> ) (p<.001)
McMillan 2012	UK	General Paediatric hospital clinic	Appointment stickers	Cohort study with historical control	Non-attendance rate	320 appointments Control: 255 Intervention: 65	46 ( <b>18.4%</b> )	6 ( <b>9.23%</b> ) (X <sup>2</sup> =4.05, p<.05)
Milne 2006	UK	Medical paediatric outpatient clinics at a children's hospital	SMS text reminders	Cohort study	DNA (did-not-attend) rate	2097 appointments  <u>New appointments, partial booking:</u> 497 Control: 341 Intervention: 156  <u>Follow-up, no partial booking:</u> 1600 Control: 1402 Intervention: 198	New with PB: 14 ( <b>4.1%</b> )  Follow-up no PB: 325 ( <b>23.2%</b> )	New with PB: 4 ( <b>2.6%</b> ) (p=.353)  Follow-up no PB: 37 ( <b>18.6%</b> ) (p=.122)
Sawyer 2002	Australia	General adolescent health clinics at a children's hospital	Telephone reminders	Randomised control trial	Non-attendance rate	171 patients Control: 70 Intervention: 101	14 ( <b>20%</b> )	8 ( <b>7.9%</b> ) (AOR 0.35, 95% C.I. 0.14-0.90, p=.029)

and Komoroski et al. (1996) followed service use of their trial participants for one year after enrolling in the study.

### **3.3.2.3 Interventions**

#### Reminders

Four of the included studies pertained to evaluations of appointment reminders sent to the patient or parent after the appointment has been scheduled, and prior to the day of the anticipated visit. Three cohort studies (two with historical controls) examined reminders delivered by SMS text message (Altuwaijri et al., 2012; Downer et al., 2005; Milne et al., 2006) and one randomised trial investigated the effectiveness of telephone reminders (Sawyer et al., 2002).

The text messages in all SMS reminder studies explicitly indicated that the message was a 'reminder' and included appointment details and a telephone number for enquiries or cancellations. In the study by Altuwaijri et al. (2012) two SMS text messages were sent to families, one five days prior to the booked appointment and a second one day prior. Five days was selected as the minimum time at which the clinic slot could be reallocated if the text message prompted a cancellation. Downer et al. (2005) sent SMS text messages three days ahead of scheduled appointments, again to facilitate re-allocation and also to avoid forgetting again after receipt of the message. Text messages in the study by Milne et al. (2006) were sent one working day in advance of the appointment, meaning that reminders for Monday appointments were received on the preceding Friday.

Sawyer et al. (2002) implemented telephone reminders one day prior to scheduled appointments. Phone calls confirmed appointment information with the family and permitted rescheduling if necessary. Three attempts were made to contact each family and leaving a message was counted as having 'made contact' or delivered the reminder.

#### Multi-faceted interventions

Two papers described interventions containing multiple components. Gatrad (2000) reported the findings of a clinical audit conducted after a period of service changes implemented as a result of an earlier audit which showed significantly poorer attendance rates in Asian families. Changes included better communication with patients and use of minority ethnic link workers; ensuring that appointments did not conflict with religious customs or holidays; making midwives aware of traditions of female seclusion in certain religious groups following births or deaths; information and persuasion via local religious leaders; collecting up-to-date contact information; telephone reminders

implemented in early evenings 24-28 hours before appointments; consultants checking the notes of non-attenders to ensure follow-up where necessary; and better 'signposting' in the hospital.

Komoroski et al. (1996) implemented an 'appointment' intervention group in which follow-up appointments were scheduled for families prior to discharge from the hospital emergency department (ED), and a written appointment notice and directions to the outpatient clinic were provided. The 'intense' intervention group were given the same treatment, but were additionally provided with a 'work excuse', travel assistance through verbal, written or social work intervention, and a discussion of childcare arrangements. This group also received a mailed reminder one week before the booked appointment, and a telephone call 24 hours prior to the clinic visit. These interventions were compared to current procedure in which families were given a telephone number and asked to call after an appropriate interval to schedule a follow up appointment.

#### Other interventions

McMillan & Jayatunga (2012) implemented a "*sticker reminder system*" for appointments in a General Paediatric clinic. However, unlike the reminders described above which were administered after the appointment had been scheduled and only a few days before the appointment was due, these stickers were given at the time of appointment booking at the end of earlier clinic visits. The sticker 'reminders' included the date and time of the follow-up appointment and were given to patients or parents.

The paper by Chariatte et al. (2007) describes an evaluation of the introduction of a hospital-wide policy stipulating that patients must pay for "*unexcused*" missed appointments, meaning those not cancelled in advance. No details were provided of the financial charge for non-attendance or the ways in which this policy was communicated to patients.

#### **3.3.2.4 Outcomes**

All studies measured non-attendance as the main outcome except the trial by Komoroski et al. (1996) which measured compliance with a recommended follow-up appointment after discharge from the ED. This was converted by the review author to a 'not kept' rate for ease of comparison with other studies.

Secondary outcomes were reported in four papers: rate of cancelled appointments (Chariatte et al., 2007; Sawyer et al., 2002); cost of SMS text reminders (Downer et al., 2005); perceived helpfulness of telephone reminders (Sawyer et al., 2002) and emergency department and clinic visits for one year post-enrolment in the study as indicators of long-term behaviour change (Komoroski et al., 1996).

### 3.3.3 Quality assessment of included studies

#### 3.3.3.1 Risk of bias in randomised control trials

Komoroski et al. (1996) reported random assignment of participants, but did not specify the method of randomisation used so adequacy of sequence generation was unclear. Sawyer et al. (2002) indicated that patients were randomised “*by the clinics they were booked to attend*” meaning that two out of four clinics each week were randomly selected for implementation of reminders. However, this was an inadequate method of random allocation and could potentially have introduced bias. This study could have been treated as a cluster randomised trial with clinics as the unit of randomisation, but the statistical tests used were inappropriate for this design and the authors presented the study simply as a randomised control trial. The method by which the clinics were “*randomly chosen*” was also unspecified.

Neither study discussed blinding of participants, healthcare professionals or outcome assessors. The trials included “*all booked*” (Sawyer et al., 2002) or “*all eligible*” (Komoroski et al., 1996) patients within the specified time periods and gave no indication of families’ choice to decline participation. It is likely that the subjects were unaware of the research given that reminders, patient support, and auditing of attendance rates are accepted practices in hospitals. Indeed, Komoroski et al. (1996) noted that informed consent was not required. It is therefore implausible that participants would have been a source of bias in either study. Moreover, both trials used objective measures from hospital records of participants’ subsequent attendance and so bias from outcome assessors was also unlikely.

In both studies healthcare professionals had no contact with families prior to their booked appointments other than to deliver the interventions. Therefore the risk of bias from this source was low, but was dependent on the intervention and control conditions being administered precisely according to the research protocols. It is possible that clinicians’ awareness of the trial and knowledge of group allocation could have affected the way in which they interacted with families when carrying out intervention or control procedures and so introduced bias. The internal validity of both studies rested on the integrity of intervention delivery.

Both sets of authors reported all specified outcomes and had no missing data due to participants lost to follow-up, so selective outcome reporting and incomplete outcome data were not problems for either study. The baseline characteristics of intervention and control groups were sufficiently comparable in both trials, except an imbalance in clinic representation in the study by Sawyer et al. (2002) as the intervention group had more patients from clinic 2 and less from clinic 4 compared to

the control group. This could have influenced the findings if there were systematic differences between clinics, but the authors assumed comparability across clinics.

Sawyer et al. (2002) reported the proportion of their intervention group that actually received the telephone reminder (87%) and noted a lower non-attendance rate for those contacted in comparison to the total (3.4% vs 7.9%). Komoroski et al. (1996) also observed that non-attendance was lower in those members of the intense intervention group who received the telephone call or were left a telephone message compared to those who were not successfully contacted (38.75% vs 62%,  $p < .04$ ). However, the proportion of those contacted and those not contacted was not reported.

Sawyer et al. (2002) stated that 140 participants were needed in each group to be sufficiently powered, but only had 101 and 70 subjects in intervention and control group respectively meaning that the study was under-powered. Yet statistical testing showed significant differences between groups. A larger sample size may therefore have revealed a larger effect size, however the problem remains that the analysis did not take account of the cluster sample design.

Komoroski et al. (1996) accounted for several potential confounding factors, observing that there were no differences between groups in terms of parents' or physicians' perception of severity of the child's illness, clinical diagnoses, parental satisfaction with treatment during their ED visit, appointment waiting times, or access to primary care physicians. As aforementioned, all scheduled appointments in this study would have been considered 'new' as patients were recruited at the time of initial referral, meaning that the type of appointment would not have been a confounding factor. Sawyer et al. (2002) reported equal numbers of new and follow-up appointments, but did not address the distribution of waiting times within their trial groups meaning that their findings could have been subject to confounding due to this factor.

Finally, in the study reported by Komoroski et al. (1996) "a few" patients were referred to sub-specialty services such as dental or pulmonary clinics rather than general medical clinics, but given the sample size ( $n=253$ ) and significant differences between groups (76% vs 53%,  $p < .001$ ; 76% vs 48%,  $p < .001$ ) this was unlikely to influence the author's findings.

### **3.3.3.2 Risk of bias in cohort studies**

#### Recruitment and selection bias

Three studies reported inclusion of all booked appointments from the specified periods in their analyses, so were not at risk of selection bias (Altuwaijri et al., 2012; Gatrad, 2000; Milne et al., 2006). Chariatte et al. (2007) excluded appointments scheduled for hospitalised patients, individuals



outside of the target age range (12-20 years old), those cancelled by healthcare professionals rather than patients, and a small number (n=63 out of a total of 35,465) where “*too much data was missing.*” However, the exclusion of these factors would not have affected the validity of the findings for the specified population and outcome. Downer et al. (2005) included all patients with a registered mobile telephone contact number in both the intervention and control cohort, meaning that the findings of this study are applicable only to families with mobile telephone numbers recorded as their preferred contact number on the hospital system. Aside from this issue, the risk of selection bias was low as the total population within the one-month time periods were included.

McMillan & Jayatunga (2012) included all booked appointments from an eight month period in their control cohort, but there was lack of clarity over the selection of patients for the intervention group. The authors reported that 65 patients were given appointment stickers at the end of initial appointments in a comparable eight month period, but it was unclear if this was all eligible patients or a selection. Furthermore, the design of control and intervention cohorts did not result in equivalent groups. Non-attendance in the control group was measured between December 2009 and July 2010, but the same period in the following year was used for *recruitment* of the intervention group. Non-attendance in the experimental cohort was actually measured up to November 2011. This difference in duration and timing of outcome assessment may have affected the validity of the findings.

#### Measurement of exposure to the intervention and outcome

None of the studies adequately measured exposure to the intervention or reported the effects of non-exposure on their findings. For example, Altuwaijri et al. (2002) highlighted in their discussion section that only 70% of patients had mobile telephone numbers registered with the hospital, but did not take account of this in their analysis. Milne et al. (2006) and Downer et al. (2005) both reported the proportion of families with mobile telephones in their SMS text reminder evaluations and accounted for this accordingly. Milne et al. (2006) compared those with mobile telephone contact numbers (31.4% for new appointments, 12.4% for follow-up) to those without, and Downer et al. (2005) reported that only 64% of patients had a registered mobile telephone number and excluded those without this from their study. However, none of these papers commented on the extent to which reminder messages were actually received, read and understood.

All participants in the intervention group of the study by McMillan & Jayatunga (2012) were explicitly recorded as having received the sticker intervention, but as mentioned above it was not clear whether there were other unreported eligible families that did not receive the intervention.

Measurement of exposure to the intervention would have been extremely difficult in the study conducted by Gatrad (2000) given the complexity and breadth of changes implemented and the fact that some components were not aimed at individual families. However, recording of some of the more simple elements of the intervention such as administration of telephone reminders could have been recorded and assessed to minimise the risk of bias.

All studies used objective measures of non-attendance from hospital records. There was therefore ostensibly little risk of bias due to outcome assessment procedures. However, it should be noted that although checking of service utilisation records is accepted as valid and objective measure of non-attendance, only one paper explicitly specified the behaviours that did and did not count as a non-attendance (Chariatte et al., 2007). In this study any cancellation, even "*at the last minute*", was counted as a cancellation rather than a missed appointment. It is unclear what criteria were used in other studies and whether these were applied consistently across control and intervention cohorts. For instance, in some organisations cancellations on the day of the appointment or late arrival at the clinic are coded as 'did-not-attends.'

#### Confounding factors

Cohort studies, particularly those conducted at single centres and with historical controls, are inherently at risk of confounding due to unmeasured variables such as social or environmental changes in clinics over time. However, most of the included cohort studies took measures to address or avoid additional confounding factors. For example, four out of the five cohort studies with historical controls used control cohorts from previous years, with the aim of making groups equivalent in terms of seasonal differences. Downer et al. (2005) compared non-attendance in a one-month period to the preceding month (September 2004 vs August 2004). However, the authors stated that historically there was little difference in attendance rates between these two months.

One possible source of confounding for Milne et al. (2006) was that differences were examined between families who had received an SMS text message and those who had not, but those who did not receive the reminder intervention appeared to be merely those families who did not have a mobile telephone contact number stored on the hospital system. Thus the differences between groups could have been a reflection of mobile telephone ownership, preferences for landline telephone contact numbers, or other factors associated with these variables such as household income, parental age, or employment status, rather than a result of the intervention.

### **3.3.3.3 Other issues related to study quality**

#### Appropriateness of study designs

Randomised control trials would have been the most appropriate research design for evaluating the majority of the intervention types discussed in this review, with the exception of monetary payments for missed appointments (Chariatte et al., 2007) and the multi-faceted approach reported by Gatrad (2000). The former would have presented ethical and acceptability issues if some families were required to pay, but others were not. The latter included several components that would have been too difficult and unethical to randomise to different families or groups, and also contained aspects that could not have been administered exclusively to the intervention group, for example the improved signposting within the hospital. Reminder systems, in contrast, are well suited to evaluation by RCT. However, the included studies of appointment reminders largely appeared to be evaluations of interventions already planned or implemented by the healthcare services, so randomisation by the researchers would not have been possible. Future study designs could be improved by conducting pre-planned, prospective evaluations, or by working with services to randomise families or clinics for controlled trials of interventions.

#### **3.3.3.4 Summary of quality assessment**

The risk of bias in the two RCT studies was generally low on the assessed criteria from the Cochrane EPOC group (Cochrane Effective Practice and Organisation of Care Group, 2013). However, the methods of randomisation were inadequate in one study (Sawyer et al., 2002) and insufficiently reported in the other (Komoroski et al., 1996), which has implications for the quality of the study and the value of the findings. There were several other minor issues that compromised the quality of these RCTs including potential confounding factors and being under-powered, though the study by Komoroski et al (1996) suffered from fewer of these problems than that of Sawyer et al (2002).

The included observational studies were generally low in selection bias, but McMillan & Jayatunga (2012) exhibited some problems with the design and reporting of their groups. The same authors explicitly noted that all participants in the intervention group received the sticker intervention, but none of the other cohort studies adequately measured exposure to the intervention or reported the effects of non-exposure on their findings. Although several studies included measures to minimise confounding factors, there remained a high risk of confounding due to the retrospective, observational and single-site research designs implemented. The quality of evidence regarding interventions to reduce non-attendance at General Paediatric outpatient clinics is therefore relatively low.

### 3.3.4 Effects of interventions

SMS text reminders reduced the rates of non-attendance by statistically significant amounts compared to no reminders in two out of three observational studies. Altuwajiri et al. (2012) and Downer et al. (2005) reported reductions of 4.4% ( $X^2=93.05$ ,  $p<.0001$ , review author's calculation) and 6% ( $X^2=6.77$ ,  $p=.0093$ , review author's calculation) in DNA rates respectively, compared to historical control cohorts. The reduction in non-attendance in the study by Milne et al. (2006) was not significant in the new appointment or follow-up appointment groups, achieving decreases of 1.5% in the former ( $p=.353$ ) and 4.6% in the latter ( $p=.122$ ). Telephone reminders were also shown to be effective compared to no reminders in one randomised control trial (Sawyer et al., 2002) demonstrating a 12.1% reduction in DNA rate (adjusted odds ratio 0.35, 95% C.I. 0.14-0.90,  $p=.029$ ).

The complex intervention reported by Gatrad (2000) achieved a 22.7% reduction in non-attendance ( $X^2=983.46$ ,  $p<.0001$ , review author's calculation), while Komoroski et al. (1996) reported 23% reduction in appointments not being kept in their 'appointment' intervention group ( $p<.001$ ) and 28% in their 'intense' intervention group ( $p<.001$ ) compared to usual practice. However, the difference in follow-up rate between these two intervention conditions was not significant.

A hospital policy of patients paying for missed appointments (Chariatte et al., 2007) had no significant effect on the non-attendance rate at an adolescent outpatient clinic with a reduction of 0.3% in DNA rate (adjusted odds ratio 0.96, 99% C.I. 0.83-1.1). Finally, the appointment sticker intervention implemented by McMillan & Jayatunga (2012) achieved a 9.17% decrease in non-attendance ( $X^2=4.05$ ,  $p<.05$ ).

### 3.3.5 Use of theory in included studies

No papers mentioned the use of any theory to inform the design of interventions. However, four studies specified behavioural predictors or causal factors of non-attendance that were to be targeted. An overview of these theoretical bases for interventions in the included studies is presented in table 3, along with the behaviour change techniques identified in the interventions, which will be discussed in the following section.

Milne et al. (2006) and Downer et al. (2005) both cited 'forgetting' as one of the main causes of missed appointments and proposed that SMS appointment reminders ought to 'remedy' or reduce this factor. Neither of the other two studies of appointment reminders described any mechanism by which the interventions were thought to operate. That is, no behavioural antecedents were cited or

**Table 3. Use of theory and behaviour change techniques (BCTs) in included studies**

Study ID	Theory described or used	Targeted predictors or causes of non-attendance	Behaviour change techniques coded by the review author
Altuwaijri 2012	-	-	'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1)
Chariatte 2007	-	-	'Future punishment' (10.11)
Downer 2005	-	Forgetting	'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1)
Gatrad 2000	-	Appointments conflicting with religious occasions	'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1) 'Credible source' (9.1) 'Restructuring the physical environment' (12.1)
Komoroski 1996	-	Practical barriers	'Problem solving' (1.2) 'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1)
McMillan 2012	-	-	'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1)
Milne 2006	-	Forgetting	'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1)
Sawyer 2002	-	-	'Instruction on how to perform the behaviour' (4.1) 'Prompts/cues' (7.1)

explicitly targeted. It could be argued that the use of reminders inherently implies an attempt to prevent forgetting, but this was not intimated by either set of authors.

Following an earlier audit published in a previous article (Gatrad, 1997), Gatrad (2000) proposed that non-attendance in the population relevant to the study was a result of appointments conflicting with religious commitments and customs in the Muslim families scheduled to attend. For example, clinic visits booked during Ramadan (a month of fasting). More precise cognitive factors were not identified and issues affecting attendance in the population's European families were not elucidated. Komoroski et al. (1996) did not mention targeted behavioural predictors in the introduction or methods sections of their study, but did state in the discussion that their multi-faceted intervention was hypothesised to work by reducing practical barriers to *scheduling* appointments, such as issues with communication skills and access to telephones, and barriers to *attending* including lack of transportation to the clinic and lack of child care for other children. However, the authors did not provide evidence of a demonstrated link between these factors and non-attendance.

The reports by Chariatte et al. (2007) and McMillan & Jayatunga (2012) offered no premises for the ways in which the studied interventions had their effects. For Chariatte et al. (2007) this may be explained by the fact that the payment intervention was the result of hospital policy and only evaluated by the authors. The study by McMillan & Jayatunga (2012) was described in a conference abstract so proposed predictors or causes of non-attendance may have been targeted, but not mentioned in their short report.

Three of the four studies that specified intervention targets did not measure these behavioural antecedents either before or after intervention implementation, making it impossible to determine whether the interventions were working as proposed. Although it may not have been feasible to adequately measure forgetting prior to intervention as the act of measurement would remind the family of the appointment. While this might be managed for intervention cohorts by asking at the time of delivery about remembering immediately preceding the intervention, it would not be possible to measure forgetting in control groups except retrospectively. Furthermore, Komoroski et al. (1996) made no attempt to measure the occurrence of proposed barriers. Gatrad (2000) did examine differences in attendance during months of Islamic religious importance in the control and intervention cohorts and found that there was no disproportionate increase in 'did-not-attends' among Muslim families during these months after service changes had been implemented. However, this demonstrates only a change in behaviour in these specified months rather than a change in clinic booking or families' priorities.

The specified behavioural predictors were addressed by at least one intervention technique in each of the four studies where target constructs were identified. However, there were also several techniques implemented by Komoroski et al. (1996) and Gatrad (2000) in their multi-component interventions that were not linked to any specified predictor. No additional justifications were given for the use of these techniques.

### **3.3.6 Use of behaviour change techniques in included studies**

Although all intervention techniques were intended to affect the attendance behaviour of patients, parents and families, none of the interventions were designed to change the cognitive or psychological predictors of behaviour. The factors specified in four studies were presented as practical and social variables, even though the acts of remembering and forgetting clearly have cognitive bases. As a result, the techniques used did not map readily to categories in the Behaviour Change Technique (BCT) Taxonomy (Michie et al., 2013), as this resource was developed for use with cognition-based interventions. Yet the implemented techniques were sufficiently similar to defined

BCTs in the taxonomy to give an indication of the mechanisms by which these interventions may have had their effects.

For example, reminders were most similar to the BCT 'prompts/cues' (BCT number 7.1), which is described as introducing a stimulus with the purpose of prompting the behaviour. Reminders also provided appointment information such as location, date and time. This aspect of the intervention may be similar to the BCT 'instruction on how to perform the behaviour' (BCT number 4.1), but is more aptly explained as providing knowledge necessary to perform the behaviour, which is not a technique specified in the taxonomy. This combination of knowledge and behavioural prompting was the core technique for the four studies investigating appointment reminders (Altuwaijri et al., 2012; Downer et al., 2005; Milne et al., 2006; Sawyer et al., 2002). McMillan & Jayatunga (2012) did not provide sufficient information on the intended procedure after stickers were given to families in clinic, but it is likely that appointment stickers also acted as prompts and as sources of information. The effectiveness of this approach however may be dependent on families revisiting the stickers between clinic visits. The intervention evaluated in Chariatte et al. (2007) was a policy to charge families for missed appointments that were not 'excused' in advance. This was definitively coded as 'future punishment' (BCT number 10.11), which is described as informing the individual that future punishment or removal of reward will be a consequence of performance of an unwanted behaviour.

The multi-component intervention reported by Komoroski et al. (1996) included scheduling an appointment rather than asking the family to telephone and make the appointment themselves. This essentially *removed* one of two behaviours that families under usual practice or control conditions were expected to carry out. Additionally, intervention families were given written notices of appointments which would act as a 'prompt' (BCT number 7.1) in the same way as the stickers described in the study by McMillan & Jayatunga (2012) and directions for getting to the outpatient clinic, akin to 'instructions on how to perform the behaviour' (BCT number 4.1). Those in the intensive intervention group were also given further 'prompts/cues' (BCT number 7.1) in the form of mailed reminders and telephone reminders, and had discussions with staff about possible child care arrangements on the day of the appointment, which was coded as 'problem solving' (BCT number 1.2). This problem solving is defined as prompting the person to generate or select strategies to overcome barriers or increase facilitators. Travel vouchers and work excuses were also provided for overcoming practical barriers, but could not be appropriately coded within the BCT taxonomy categories as they did not involve any change in the cognition of the recipient.

The study with the most included BCTs was that of Gatrad (2000). Out of the eight strategies described in this paper, one was intended to improve follow-up of non-attending families after

missed appointments had occurred and so was not considered a BCT for reducing non-attendance. Four more were intended to remove or overcome practical barriers such as language issues, communication errors, conflicting religious commitments, and expectations to attend at inappropriate times. These were not cognition-based and so were not coded under the BCT taxonomy. The remaining three strategies were coded under four BCT categories. Asking community elders to impress on families the importance of attending was coded as a 'credible source' (BCT number 9.1) in favour of attending, and asking the same elders to draw attention to the hospital's communication services was coded as 'instructions on how to perform the behaviour' (BCT number 4.1). Telephone reminders were again coded as 'prompts/cues' (BCT number 7.1), and improving signposting in the hospital was coded as 'restructuring the physical environment' (BCT number 12.1). This encompasses changing the environment in order to facilitate performance of the wanted behaviour, although arguably the majority of families arriving at the hospital would be highly unlikely to then miss their appointment.

### **3.4 DISCUSSION**

#### **3.4.1 Summary of findings**

This chapter describes a systematic review of research evaluating interventions to reduce non-attendance at General Paediatric outpatient appointments. Few articles were found that met the inclusion criteria, with six observational cohort studies and two randomised control trials included in the final review. Interventions included reminder systems, a financial penalty policy, and multi-component approaches.

##### ***3.4.1.1 Reminder systems***

Appointment reminders sent by SMS text message were effective at reducing non-attendance in two out of three cohort studies. The third study was potentially confounded by the method of group selection used. As such, only modest claims can be made about effectiveness, given the low number of articles and the use of observational designs with historical controls. However, both Altuwaijri et al. (2012) and Downer et al. (2005) reported decreases in non-attendance that would be clinically and financially valuable, and more high quality evaluations are recommended to bolster the evidence for effectiveness of text message appointment reminders.

There was also some evidence that reminders administered by telephone were effective. However, this evidence came from only one study which, despite a randomised control design, was of limited quality due to inadequate randomisation, uneven distribution of clinic membership across groups, untested potential confounding factors (e.g. waiting times), and being statistically under-powered.



Consequently, no firm conclusions can be drawn from this research about the effectiveness of telephone-based reminder systems.

#### ***3.4.1.2 Multi-faceted interventions***

Two articles reported evaluations of different multi-component interventions. The first, described by Gatrad (2000) appeared to be very effective and included eight separate components targeting families, local communities, healthcare professionals, the outpatient service, and the hospital environment. Unfortunately the breadth and complexity of implemented changes meant that monitoring of exposure to each element of the intervention was not possible. This not only limits the trustworthiness of the findings, but prevents consideration of the effectiveness of each component. This is a particular problem as the intervention included appointment reminders which could have independently accounted for a large proportion of the reduction in missed appointments. The use of a historical control also means that confounding factors cannot be ruled out. Effectiveness of this intervention cannot therefore be claimed unequivocally, and further research would be required before this complex approach could be recommended for use elsewhere.

A randomised control trial reported by Komoroski et al. (1996) found their multi-faceted intervention to be effective at reducing non-attendance. The study had few quality issues and fairly low risk of bias, but included several aspects that were inadequately reported and the effectiveness of each component of the intervention was not elucidated. Nonetheless, this research provides moderate evidence that an intervention including appointment provision, travel assistance, a 'work excuse', discussion of childcare arrangements, and two reminders, is effective at reducing non-attendance. However, clarification of randomisation methods and intervention techniques would be required, and replication of this positive finding in another setting desirable, before this intervention could be recommended for use in clinical practice. Moreover, the possibility that the effectiveness of the intervention was due mainly to the inclusion of appointment reminders should be investigated.

#### ***3.4.1.3 Other interventions***

An appointment sticker system described by McMillan & Jayatunga (2012) appeared to be very effective using a simple and inexpensive system. Yet the study was somewhat flawed by differences in timing of the measurement of the outcome between the intervention group and historical control. No firm conclusion can therefore be drawn from this article about the effectiveness of the intervention.

A financial penalty intervention had no significant effect on non-attendance rates, but data were combined from several years of hospital records giving a comparison of five years pre-intervention to

three years post-intervention. These large and uneven groups may have masked changes in non-attendance rates at the time of implementation of the policy which could have been captured with analyses that were less broad. From this study it might be concluded that financial penalties for missed appointments are ineffective, but the study design means that this finding is open to scrutiny.

#### **3.4.1.4 Theories and behaviour change techniques**

No studies reported using any theory as a basis for intervention design, and very few references were made as to the mechanisms by which authors expected the interventions to work. No cognitive, emotional or social antecedents of behaviour were considered. Behaviour change techniques were not used explicitly in any intervention study, but six BCTs were identified through coding with the BCT taxonomy (Michie et al., 2013). The most common were using prompts and providing instructions about how to perform the behaviour. Six of the seven interventions containing these techniques were successful in significantly reducing non-attendance rates, though the studies varied in quality.

#### **3.4.2 Relationship to the literature**

The finding that SMS text message reminders are effective at reducing non-attendance rates accords with the results of several high quality systematic reviews which included studies from a range of adult and paediatric, and primary and secondary healthcare services (Car et al., 2012; Gurol-Urganci et al., 2013; Guy et al., 2012; Stubbs et al., 2012). This further supports the conclusion that appointment reminders sent by text message are likely to be a worthwhile strategy in General Paediatric clinics.

The existing evidence regarding telephone appointment reminders is also positive. For example, reviews by both Stubbs et al. (2012) and Gurol-Urganci et al. (2013) found that telephone reminders had similar effectiveness to text messages in reducing missed appointments across a range of clinics, and Hasvold & Wootton (2011) reported that telephone reminders made by healthcare staff were more effective than automated phone calls or text messages. This suggests that despite the quality of evidence from the current review being low due to poor study design, telephone reminders may yet be a useful intervention for non-attendance in paediatric outpatient settings.

There are few studies evaluating financial penalties for reducing missed appointments, particularly in paediatric services. This is possibly due to practical and ethical issues in implementing such policies. Bech (2005) also notes that in some countries and healthcare systems it may not be legal to charge fines for non-attendance at appointments. For example, in the Netherlands it only became legal to impose financial penalties for missed hospital appointments in 2004, but this did not extend to

appointments in primary care. One study that empirically investigated the effects of a 'service fee' for appointments that were not attended, cancelled or rescheduled found that missed appointments decreased significantly from 18% to 10% after implementation at a university student health centre in the United States (Wesch et al., 1987). Lesaca (1995) also reported that a \$30 'no-show' fee levied on appointments missed at an adult community mental health centre in the USA reduced non-attendance from 20% to 9%. These results indicate that in healthcare systems that permit financial penalties, fines can reduce missed appointments in adult health clinics. However, this is unlikely to be suitable in paediatric clinics in the United Kingdom where it is acknowledged that penalties could put vulnerable children at risk of not being seen by healthcare services (Pearson, 2008).

No other studies have been found using a similar appointment sticker system to that described by McMillan & Jayatunga (2012). However, this first study indicates potential effectiveness of this intervention which ought to be further investigated using improved methods and research design.

Similarly few published studies have reported the use of multi-component approaches to reduce missed appointments in paediatric healthcare settings. However, some authors have previously proposed that appointment reminders alone are insufficient to significantly improve attendance. For example, Friman et al. (1987) argued that to be effective reminders needed to be "*enhanced with other ways of reducing patient effort.*" Consequently, in two studies conducted in direct access paediatric clinics in the USA, these authors demonstrated that mailed and telephone appointment reminders in combination with free parking passes were successful in reducing missed appointments (Friman et al., 1985; Friman et al., 1987). It is possible that such strategies with multiple techniques could reduce non-attendance rates in General Paediatric clinics even further than reminders alone, but caution is required to ensure that extra components are truly adding value to the intervention rather than incurring unnecessary additional cost. Future research should be designed so that the effects of intervention components can be evaluated individually. This would likely be facilitated by the use of theory to explain the purpose of each element in an intervention and better description of each technique using the BCT taxonomy.

### **3.4.3 Limitations of the systematic review**

This systematic review is limited by some aspects of the search strategy and inclusion criteria. First, only articles available in full-text in English were included meaning that potentially relevant intervention studies in other languages were missed. There were also six articles identified by the literature search that could have been appropriate for inclusion, but were unobtainable in full-text in the time-scale of the review. This was predominantly due to the studies being published in old, out of

print or obscure journals. Furthermore, grey literature was searched only through databases of dissertations, theses, and conference proceedings. As a result, non-academic grey literature such as individual hospital reports may have been overlooked, though known health policy documents were checked for references to relevant interventions and high quality evaluations are unlikely to have been published only in clinical sources.

Despite these shortcomings, this review achieved its aim of providing an overview of existing interventions, their apparent effectiveness, and the use of theory and behaviour change techniques in their development. This is sufficient for the purposes of the PhD, but relevant missing studies and non-English studies ought to be included if the review is replicated for peer-reviewed publication.

#### **3.4.4 Implications**

From the systematic review alone, cautious recommendations can be made to healthcare providers that appointment reminders sent by text message are likely to be useful in reducing non-attendance at General Paediatric outpatient clinics. However, any such implementation ought to be evaluated using high quality methods to support the literature on this intervention. No other strategies can be advocated at this stage, though reminders by telephone, appointment stickers, and strategies delivered in combination with reminders may all prove to be helpful approaches in future evaluations.

With regards to future research, it is clear that several identified interventions require more high quality research before conclusions can be drawn about their effectiveness in General Paediatric settings. Moreover, by neglecting to consider the processes underlying intervention effects, authors were unable to elucidate how and why their strategies were successful or unsuccessful in changing behaviour, thereby precluding refinement of interventions. Use of intervention development approaches that recommend targeting specific behavioural antecedents with specific behaviour change techniques would be advantageous, alongside consideration of underlying theories that explain non-attendance in this context. In particular, social and psychological factors have thus far been neglected in the intervention literature and ought to be a primary focus in future research.

#### **3.4.5 Conclusion**

This systematic literature review has shown that there are few studies that have been conducted assessing the effectiveness of interventions to reduce non-attendance at General Paediatric secondary care services. Only two studies were found that reported randomised control trials in this area, and the quality of evidence is low to moderate. The findings suggest that text message reminders are likely to be effective at reducing missed appointments, but the evidence regarding

other interventions is inconclusive. The lack of theory in the development of interventions means that it is unclear why text message reminders are effective and the processes by which they change behaviour. No interventions considered the social, psychological or cognitive factors related to attendance. It is therefore important that research is conducted into these individual parental factors which could be targeted in an evidence and theory-based intervention, and which could explain the effectiveness of text message appointment reminders.

The following chapter will consider existing non-attendance management strategies from the perspective of healthcare professionals and their beliefs about the reasons for missed appointments. The findings will elucidate the reasoning behind current practice, for example why reminders and removal of practical barriers have been targeted in published interventions, but parental beliefs have been neglected. The subsequent chapters will investigate parental psychological factors associated with non-attendance that could be targeted in future interventions.

## CHAPTER FOUR

### 4. Qualitative interview study with healthcare professionals and service providers

#### 4.1 INTRODUCTION

The previous chapter highlighted that existing management of non-attendance at General Paediatric clinics, at least in published interventions, consists mainly of appointment reminders to prevent forgetting and strategies to remove practical barriers to attending. It is apparent that interventions have not been developed based on any formal or informal theories of behaviour, nor have they included any consideration of parental attitudes and beliefs. This may be due to gaps in the literature regarding theory and cognition in relation to factors associated with non-attendance, as described in the introduction chapter. However, it may also be related to the fact that management decisions about missed appointments are highly dependent on the views of clinicians and other decision-makers within healthcare organisations about the underlying causes of non-attendance and appropriate intervention strategies.

Previous studies have investigated the influences of healthcare staff's perceptions on the management of missed appointments in primary care settings. GPs in one study attributed appointments missed by adult patients mainly to patient factors, or *"what's going on in their lives"*, rather than issues related to the healthcare service, and underestimated the value patients placed on the doctor-patient relationship (Martin et al., 2005). These doctors perceived non-attendance to be somewhat beneficial in allowing them to catch up on paperwork and had sympathy for patients with difficult circumstances who struggled to attend, though they were less forgiving of patients who appeared as though they *"couldn't care less"* about appointments. Perhaps because non-attendance was not perceived to be hugely problematic, healthcare staff did not support interventions such as telephone or postal reminders, dedicated answering machines for cancelling appointments, or financial penalties, due to the anticipated expense, time and difficulty in implementing these approaches. Instead, simple and inexpensive strategies such as encouraging posters and appointment cards were advocated. Another study in the USA found that primary care physicians believed that non-attendance occurred as patients did not value preventive services and struggled with travel costs, leading doctors to suggest patient education and telephone consultations as appropriate alternatives (Zeber et al., 2009).

These examples demonstrate the influence of healthcare providers' views on decisions regarding management of missed appointments. Similar studies investigating the views of healthcare professionals (HCPs) about appointments missed by children in secondary care outpatient clinics are

lacking. Non-attendance prevention and management approaches in these settings are influenced not only by secondary care doctors and other HCPs, but also service managers and executive decision-makers, as well as GPs and primary care HCPs who refer patients and follow up non-attendances, and potentially also commissioners and primary care executives who have a say in the ways that secondary care services are organised. It is therefore important that the views of all of these groups are represented in the following study.

The aim of this qualitative research was to explore healthcare providers' beliefs regarding the reasons for non-attendance at paediatric outpatient clinics and their views on how non-attendance should be managed.

## **4.2 METHODS**

This study was conducted in collaboration with another researcher, Gemma Heath (GH). All data collection tasks including approaching participants, interviewing and transcribing data were carried out by both researchers together, with some input at the preliminary coding stage from PhD supervisors. Early coding of the data and generation of themes were also a collaborative effort, but production of the final findings was the responsibility of the author (EC). This study has been published as a peer reviewed article in the journal, *Family Practice* (Cameron, et al. 2013).

### **4.2.1 Sampling**

Semi-structured interviews were carried out with clinicians, managers, executives and commissioners from Birmingham Children's Hospital and three nearby Primary Care Trusts (PCTs). To obtain sufficient data from individual groups, approximately 30 interviews were estimated to be required (Morse, 2000). Key informants with experience of contact with, planning, or delivering secondary paediatric outpatient clinics were identified through discussion within the research team and were purposively sampled. Additional 'snowball sampling', where interviewees suggest potentially useful contacts, identified other professionals with relevant perspectives. Prospective participants were invited by email and followed up by telephone. Recruitment and data collection ended when no new information was identified, and data saturation was reached (Bradley et al., 2007).

### **4.2.2 Interviews**

Interviews were conducted at participants' workplaces between May and September 2010, and took 40 minutes on average. Informed consent was obtained, including acknowledgement of job title disclosure, as professional roles provide important context. A semi-structured interview schedule

was used, allowing flexible exploration of salient responses (Table 4). Interviews were recorded and transcribed verbatim. This study was confirmed by the National Research Ethics Service as a service evaluation not requiring review by an NHS Research Ethics Committee.

**Table 4. Topics covered in the semi-structured interview schedule and example questions**

Interview Topics	Example Questions
Access to paediatric outpatient services	<i>“How easy or difficult do you think it is for families to come for an outpatient appointment at the hospital?”</i>
Perceived reasons for non-attendance at appointments	<i>“Why do you think some families do not attend outpatient appointments?”</i>
Ways of managing non-attendance	<i>“What do you think could be done to prevent non-attendance?”</i>
Perceptions of families’ views and experiences	<i>“How do you think adolescents feel about visiting the children’s hospital outpatient department?”</i>
Working across the primary-secondary care interface	<i>“How do you feel about the current children’s hospital outpatient services and their referral system?”</i>
Delivering paediatric outpatient care in community settings	<i>“How would you feel about having a General Paediatric hospital outpatient clinic at your practice?”</i>
The location and design of services	<i>“How well does the environment of the outpatient department meet the needs and expectations of families?”</i>
	<i>“Where do you think the best place for community-based clinics would be?”</i>

#### **4.2.3 Data Analysis**

Interview data were coded by the author and two colleagues (GH and Sabi Redwood) and analysed following the five stages of a thematic framework approach: familiarisation; identifying a thematic framework; systematically applying the framework to the data (indexing); creating a summarised matrix for each theme (charting); and interpretation (Ritchie & Spencer, 1994). More detailed information about thematic framework analysis is provided in chapter five. Codes pertinent to access



and attendance were identified for further investigation. The coders met throughout the analysis period to discuss theme development and interpretation.

### 4.3 FINDINGS

Thirty-seven healthcare staff from primary and secondary care participated, as shown in Table 5. The analysis generated five themes, which will be described below.

**Table 5. Participant characteristics**

Primary Care	Secondary Care
6 General Practitioners (GPs)	9 Consultants:
1 Other Healthcare Professional (HCP):	6 General Paediatrics
1 Health Visitor	1 Respiratory Medicine
1 Manager	1 Dermatology
2 Executives	1 Emergency Medicine
2 Commissioners	3 Paediatric Registrars:
	1 Neurology
	1 Metabolic Diseases
	1 Paediatric Intensive Care
	5 Other Healthcare Professionals (HCPs):
	3 Clinical Nurse Specialists
	1 Phlebotomist
	1 Occupational Therapist
	3 Managers
	5 Executives
<b>Total = 12</b>	<b>Total = 25</b>

#### 4.3.1 Perceived barriers to attending appointments

Participants suggested the following barriers to families attending appointments: travel and parking issues; general ‘access’ difficulties; poor administration of appointment letters; conflicting priorities such as school, work or illness; lengthy waiting times; many scheduled appointments; and forgetting. General Practitioners focused on the real-life practicalities for families, highlighting financial costs and ability to pay; particular difficulties for parents travelling with several young children by public transport; and the impact of “other more pressing social problems” (GP 2).

*“You know, if you’re about to be evicted from your house... the last thing on your mind is taking little Johnny or little Jane to the children’s hospital. You’re more interested in keeping a roof over your head, putting food on the table. Let’s be realistic about it.” (GP 2)*

Hospital doctors and specialist nurses acknowledged that travel difficulties may cause “tremendous aggravation” (Consultant 7), but asserted that such access issues do not ultimately affect attendance. Instead it was suggested that supposed barriers might be due to unrealistic parent expectations, and that access was in fact reasonable. Two hospital-based interviewees proposed that the degree to which attendance is influenced by access barriers depends on parents’ motivation.

*“For those people who are motivated to bring their young person to clinic, it doesn’t cause a barrier because nothing would, but for those where anything is going to cause a problem, we’re not the easiest to get to.” (HCP 5)*

#### **4.3.2 Perceptions of parents’ values, attitudes and beliefs**

The majority of participants perceived that parents’ attitudes and beliefs had at least some influence on attendance. GPs, managers, executives and commissioners cited parents’ perceptions of appointment necessity and importance, and their motivation to attend. They claimed that some parents find them “too much hassle” (Manager 4) or that they “don’t want to go” (Commissioner 2).

Hospital-based doctors and other HCPs also referred to parents’ motivations to attend, such as the value placed on the relationship with the doctor, the influence of previous negative experiences at the hospital, and concerns about wasting clinicians’ time. Hospital staff discussed the influence of parents’ perceptions of the child’s condition, whether it is considered problematic or resolved, and their level of anxiety.

*“If parents have got a concern about their child, they will more likely than not follow that through... if they have been told that there is a concern or a worry that they are not concerned or worried about, if the child’s slightly overweight or has some behavioural difficulties that the parents aren’t worried about, I think in that situation they are highly unlikely to attend.” (Paediatric Registrar 1)*

Hospital consultants, specialist nurses and executives suggested that non-attendance may be related to the value placed on the child’s health.

*“Some families that are far more concerned about themselves than their child actually... it’s more important to go and do something because they want to do that as an adult, rather than actually the child needs to be reviewed.” (HCP 1)*

Many hospital-based participants also cited more serious child protection issues as a factor associated with non-attendance, suggesting that some appointments are missed for “more sinister reasons” (Consultant 8).

### 4.3.3. Views on the characteristics of families who do not attend

Participants from all groups proposed links between attendance and demographic factors, including socio-economic status, educational level and ethnicity. Missed appointments by minority ethnic families were explained by language issues, cultural beliefs, and previous experience. However, one HCP pointed out non-attendance is not entirely predictable from demographic factors.

*“There are pockets of those patients... that I could equally say you know, they will definitely come and they’re in that socio-economic group [socio-economic groups 4 and 5], because they have the perception that they don’t want to waste your time and so there’s a personality thing as much as it is a socio-economic thing.” (HCP 5)*

GPs and hospital-based doctors proposed a greater likelihood of non-attendance in ‘chaotic’ or dysfunctional families. GPs linked family ‘dysfunction’ to social factors, such as “poor educational abilities” (GP 2). Consultants thought that other issues may take precedence in their lives, they lack organisation, and “don’t run on diaries” (Consultant 9).

*“Because they’ve got a chaotic life and they don’t, they haven’t really sort of put that right up at priority one, or they don’t have system for making something priority one.” (Consultant 2)*

Moreover, hospital-based consultants and other HCPs claimed that there were distinct types of families, suggesting that they perceive attendance as a relatively fixed characteristic of families.

*“I think your general attenders are your general attenders, I think your non-attenders are your general non-attenders.” (Consultant 8)*

### 4.3.4 Potential strategies for reducing non-attendance

All groups recommended confirmation or reminder systems, and improved communication processes with families. Participants in primary care also proposed shorter waiting times, increased flexibility and convenience. Hospital interviewees suggested new ways of delivering services such as evening clinics, suspended appointments, and multi-appointment ‘one-stop-shop’ visits. They also recommended improved transport links; sufficient appointment notice; and greater choice over appointment time and location.

GPs, and managerial and executive-level decision-makers from primary and secondary care were largely in favour of providing ‘care closer to home’ in community settings, though some claimed that effectiveness would depend on the specific transport links and location of such services. Many hospital doctors felt strongly that despite potential other benefits, such services would have no effect on attendance.

*“They don’t make a hoot of difference to health really or to DNA rates.” (Consultant 7)*

Two hospital-based HCPs advocated addressing parental motivation by penalizing families who miss appointments through monetary fines or withholding treatment, but acknowledged this would be difficult to implement. Other interviewees saw this as unfair and detrimental to children's wellbeing. Educational approaches were also proposed by hospital-based participants, with managers and executives focusing on the costs and consequences of missing appointments, while doctors and HCPs emphasised knowledge of the reason for the appointment, and their rights and responsibilities around cancelling appointments.

#### **4.3.5 Roles and responsibilities in managing non-attendance**

In accordance with local policy, hospital consultants, managers and executives stated that referring GPs were informed when appointments were missed. However one hospital manager expressed concerns about 'passing the buck' and uncertainty about the thoroughness of GP follow-up. Hospital consultants and HCPs suggested that they should retain responsibility for following up certain cases depending on the appointment type and perceived urgency.

*"I think follow-up DNA's we do have a responsibility for because it's us that's asked for the appointment, we know the problem we're dealing with and then we can make a decision about whether it matters or not. And if it matters then we chase up the patient."*  
(Consultant 4)

An emphasis on adequate follow-up to ensure child safeguarding was apparent in the interviews of many clinical and non-clinical hospital participants.

*"...one or two missed appointments and are we actually talking about a child protection issue? ...I don't feel that we could a hundred percent say that we're confident, that we follow all these kids up and can say categorically no there isn't."* (HCP 1)

To prevent missed appointments, some consultants thought that GPs could "tighten their referring practice" (Consultant 6) to ensure appropriate referrals, and educate families about the importance of attending. One GP, however, was hesitant to interfere with parental responsibilities, instead suggesting that the role of the GP is limited to family support and re-referral. Three hospital-based interviewees echoed this sentiment that parents are ultimately responsible for ensuring attendance, and should be encouraged to choose for themselves, but one GP and one registrar noted that these parental choices can result in missed healthcare for children.

*"...it's not the children who are not attending, it's the parents who aren't bringing them."*  
(Paediatric Registrar 3)

## **4.4 DISCUSSION**

### **4.4.1 Summary**

All groups suggested that attendance is influenced by practical barriers, parental beliefs and socio-demographic factors. GPs perceived the greater influence to be situational difficulties, while hospital-based HCPs presented parents' perceptions as the dominant factor. The latter attributed more personal causes, and therefore classified families as 'attenders' or 'non-attenders'. Non-clinical participants cited both factors, but presented less detailed insights. Accordingly, GPs and primary care interviewees focused on reducing barriers and forgetting, tended to be in favour of community-based clinics, and limited their role to reactive follow-up of missed appointments. Hospital staff suggested more educational and behavioural approaches to prevention, were sceptical of the effectiveness of 'care closer to home' for reducing DNA rates, and were keen to target parental beliefs.

### **4.4.2 Interpretation of the findings**

Divergent views on the occurrence and management of nonattendance may be explained by the professional context and orientation of different groups. Secondary care professionals often have relatively short-term relationships with families and direct knowledge of missed appointments in a hospital setting. They may, therefore, focus on available transport links and the number of families who *do* manage to attend appointments, rather than individual practical difficulties. This group might consider more novel prevention strategies, as missed appointments have an acute impact on their practice and the success of traditional approaches may have levelled off. Additionally, staff working in a children's hospital are child focused and prioritize the needs of the child patient over those of the whole family. This explains their emphasis on child protection, willingness to intervene in non-attendance and hesitance to rely solely on GP follow-up of missed appointments.

Conversely, GPs have regular contact with families so are likely to have a greater understanding of the practical and social difficulties faced by parents and the specific requirements of travelling to hospitals from their locality, thus explaining their focus on barriers. Moreover, parents may emphasize practical difficulties when explaining missed appointments to GPs to avoid blame and maintain positive relationships. Similarly, some GPs may prefer not to address motivational issues in case this harms their rapport with families. A previous study found that GPs were cautious about addressing adult missed appointments in primary care for this reason (Husain-Gambles et al., 2004). GPs also retain the notion of being a 'family doctor'; they address the needs of whole families and

treat child patients within this context. Their support for parental autonomy and responsibility may be related to this promotion of the primacy of the family unit.

This difference in focus between primary and secondary care professionals, whereby hospital clinicians protect the needs of the child and GPs prioritize the needs of the family, may be two reflections of a trend in healthcare provision in the UK to promote patient-centred rather than paternalistic care. The paternalistic model of consultation generally involves the doctor making decisions on behalf of the patient and providing them with instructions, while the patient-centred approach involves the patient or family making informed choices about their own care, and shared-decision-making with the doctor (Coulter, 1999). GPs in this study indicated a preference for supporting and re-referring families who had missed appointments, and were reluctant to interfere with parental choices about attendance. Instead they wanted to provide greater choice and flexibility to families around the time and location of appointments. This suggests that these professionals respect the right of parents to make autonomous decisions. They position families, and parents in particular, as recipients of 'patient-centred' care.

Hospital-based clinicians too advocated strategies that improved access and choice around appointments. However, they were also more critical of parents' reasoning and more willing to intervene in parental behaviour as a result of predominant child safeguarding concerns. This may be because hospital staff advocate patient-centred care truly at the level of the patient rather than that of the parent or family. In the case of children, patients may be too young to participate in informed or shared decision-making. Instead, secondary care providers focus on children's medical needs and their right to healthcare, which may be in opposition to parental priorities. This alternative interpretation of 'patient-centred care' focuses on protecting children's right to timely medical care, rather than the family's right to make decisions about when and where health services are accessed. Hospital staff may support a parent's right to make informed decisions about their child's care, but this would always be secondary to the perceived needs of the child. This stance may mean that under some circumstances hospital clinicians appear paternalistic in their manner as they make demands of parents to protect the rights of the child patient, though they might argue that this constitutes a 'patient-centred' or child prioritizing approach.

Though divergent staff perceptions can be explained by alternative professional priorities and differences in interpretation of 'patient-centred care', the difference in views regarding responsibilities for dealing with non-attendance may be a barrier to effective management of missed appointments.

#### **4.4.3 Relationships to the literature**

Participants in this sample were aware of the majority of factors identified in the literature and presented in the introduction chapter as influencing attendance, including access barriers, service issues and parent decision making. Interviewees acknowledged links between attendance and socio-demographic factors but presented relatively nuanced views. For instance, ethnicity was thought to affect attendance mainly through the influence of language and cultural beliefs, supporting a previous study that showed that differences in non-attendance rates between ethnic groups were not significant when culturally appropriate measures were implemented (Gatrad, 2000). While participants noted that non-attendance might be more likely in lower socioeconomic groups, it was emphasized that social background is not sufficient to explain non-attendance. As one interviewee indicated, parents from deprived backgrounds may nevertheless be motivated to attend, suggesting an over-riding influence of parental beliefs.

The notion of 'chaotic families' cited by healthcare staff also accords with earlier findings that non-attendance is higher in families with 'diffuse social problems' (Cooper & Lynch, 1979) and who have contact with social services (Watson & Forshaw, 2002). Patients with 'chaotic' lifestyles were also mentioned in previous qualitative studies of staff views in primary care settings. One GP in a study by Martin et al. (2005) stated that, "*some people's lives are so chaotic they are incapable of remembering things.*" This closely reflects the statements in our study that these families were disorganized and had no systems for prioritizing appointments. 'Chaotic lives' were also mentioned by GPs in studies by Hussain-Gambles et al. (2004) who ascribed this trait to young people in particular, and by Gill et al. (2012) who noted this as a source of powerlessness preventing them from influencing child hospital admissions.

Additionally, our interviewees referred to non-attendance as a fixed characteristic of patients and families. This was also mentioned by healthcare staff in the study by Hussain-Gambles et al. (2004) who referred to "*repeat offenders*", and there is existing evidence to suggest that non-attending families are significantly more likely to have also missed previous appointments (McClure et al., 1996).

#### **4.4.4 Implications and recommendations**

The findings presented here show that, similarly to earlier studies in primary care, healthcare providers' views about reasons for non-attendance and about families who miss appointments, are closely linked to their beliefs about the best ways to manage non-attendance. While GPs focus on practical barriers to attending and maintaining the autonomy of the parent in decisions about their

child's healthcare, hospital clinicians are much more attuned to the influences of parental decision-making and are enthusiastic about approaches that go beyond improving access to clinics and forgetting. Hospital-based staff demonstrated a desire for interventions that target parental cognitions and behaviours. However, management of missed appointments at the time of the study consisted of some provision of care 'closer to home' in outreach settings to reduce access barriers and the beginnings of a programme to deliver appointment reminders by text message to prevent forgetting. This failure to implement strategies targeting parents' beliefs and attitudes despite staff interest may be due to a lack of knowledge about which parental cognitions to target, and the ways in which parents' behaviours might be changed. As described in the introduction chapter and the systematic literature review chapter, there is a gap in the literature regarding theories and interventions in this area. Consequently, future research must involve treatment of non-attendance at paediatric outpatient appointments as a behaviour with cognitive antecedents that can be targeted. Relevant cognitions must be investigated, followed by the development of theory about how cognitions interact to affect attendance, and development of interventions to target viable cognitive factors. This would provide hospital clinicians with theory-based strategies to target parents' attitudes and beliefs, and to protect child health.

#### **4.4.5 Strengths and limitations of the study**

This is the first qualitative study to investigate healthcare professionals' views of non-attendance at secondary paediatric outpatient clinics. The study benefited from a diverse sample, though it is acknowledged that the majority of participants came from secondary care. This was due to difficulty recruiting busy GPs and the potentially greater resonance of the topic with staff in the children's hospital. Multiple researchers analysed and interpreted the data, thereby lending credibility to the findings.

#### **4.4.6 Conclusion**

This qualitative study of healthcare providers' views has provided an overview of current approaches to management of non-attendance at paediatric outpatient appointments, and their links to clinicians' and other decision-makers' beliefs about reasons for non-attendance and responsibilities regarding missed appointment management. Hospital-based healthcare professionals support the use of interventions that target parents' attitudes and beliefs, as well as those that address forgetting and barriers to access. However, there is no existing literature on theories or interventions related to parental cognition in this area, which could be used to devise new management strategies. Further research is therefore required to investigate parental cognitions related to attendance and non-



attendance, which can then inform the development of a theory regarding non-attendance and recommendations for interventions. The following chapters will address these research needs by investigating parental cognitions through qualitative and quantitative approaches.

## **CHAPTER FIVE**

### **5. Qualitative interview study with parents**

#### **5.1 INTRODUCTION**

The previous chapters have illustrated that there has been no prior research investigating social or psychological factors associated with parental non-attendance at children's general medical outpatient appointments. No theories have been developed to explain this behaviour, and subsequently no behavioural interventions have been developed. This means that interventions targeting forgetting and practical barriers have been predominant, despite hospital-based healthcare professionals recognising a need for strategies that target parents' attitudes and beliefs.

The aim of this parent interview study was therefore to identify the cognitive factors that influence attendance at General Paediatric outpatient appointments provided by Birmingham Children's Hospital. To achieve this aim, the specific objectives were to describe parents' values, attitudes, and beliefs in relation to attendance, and to examine their prior experiences of attending and missing appointments.

#### **5.2 METHODS**

##### **5.2.1 Ethics**

Ethical approval was obtained from the West Midlands NHS Research Ethics Committee (see appendix 1.1) and the Life and Health Sciences Research Ethics Committee at Aston University (see appendix 1.2). Research and development approval was also granted by Birmingham Children's Hospital NHS Foundation Trust.

The main ethical concern in this study was to ensure that interviewees were aware that participation was entirely voluntary and would in no way impact on the healthcare of their children. To achieve this, healthcare professionals were intentionally not involved at any stage of recruitment or data collection. Furthermore, the voluntary nature of the study, participants' right to withdraw, and anonymization of data were emphasised prior to interview. Informed consent confirming participation under these conditions was obtained from all participants. In addition, data collection procedures were informed by relevant BCH staff policies, including guidance on lone working in people's homes and handling potentially sensitive information or child protection issues.

### **5.2.2 Sampling**

Participants were selected through purposive sampling in order to provide insight and 'information-rich' accounts of the topic of interest (Patton 2002), as well as a diverse range of views and experiences. A 'snowball' sampling method was also employed to capture potentially relevant individuals within the networks of already-recruited parents (Braun and Clarke 2013). The only inclusion criteria were that the participant was a parent or caregiver to a child who had previously attended or missed at least one General Paediatric outpatient appointment scheduled with BCH, and that the participant was able to provide informed consent to take part (with the aid of an interpreter if necessary).

To ensure that the widest range of influencing factors could be identified, views were sought from parents with differing attendance histories and who were scheduled to attend appointments in different clinic settings, including the main hospital and two community-based outreach sites. A moderate to large sample size was therefore required (Braun and Clarke 2013) to provide enough data to fully explore the research question in relation to each type of experience. Consequently, a target sample of approximately 30 parents was specified (Baker and Edwards 2012). This was estimated to be sufficient to achieve saturation, the point at which no new information is obtained from additional data (Morse 1995), without being so large that the analysis would become unmanageable or the findings superficial (Ritchie, Lewis et al. 2003). Although this provided a target figure around which recruitment could be organised, it was intended that data collection would end when data saturation was reached. Therefore the early steps of analysis (transcription, familiarisation, and open coding) were conducted for completed interviews alongside ongoing recruitment. It was intended that when additional interviews provided no new views or dimensions of experience relevant to the research aim, recruitment and data collection would cease.

### **5.2.3 Recruitment**

Recruitment took place in six phases between July 2011 and November 2012. The first two phases were carried out in collaboration with a second researcher, Gemma Heath (GH), who was recruiting parents and children for a qualitative study on experiences of different healthcare 'spaces'. Given the similarities between the two projects in terms of sampling, time and resources were pooled to maximise recruitment into both projects. The studies were presented to potential participants as distinct components of one wider research programme investigating views and experiences of General Paediatric healthcare. Recruited adults were alternately allocated to each study to ensure a roughly even and fair distribution of participants for each researcher, unless a parent explicitly

reported previously missing appointments in which case they were interviewed for the current study regarding attendance.

Postal invitations were used as the main recruitment method for this study. Potential participants were identified by hospital information technicians using patient records as a sampling frame. Parents of children who had attended or missed General Paediatric appointments up to one year previously were selected and sent an invitation letter (see appendix 1.3) and information sheet (see appendix 1.4) about the study. They were requested to contact the research team by telephone, email, or by sending back a written contact information form in the provided reply-paid envelope if they were interested in taking part. All responses were followed up by phone call to confirm willingness to participate and to schedule a time for interview. Additional approaches with amended recruitment documents were implemented during different phases of recruitment, as described in the following sections. The numbers of participants recruited through each method in each phase are presented in table 6.

#### Recruitment phase one – main hospital

Three-hundred letters were sent to parents of children scheduled to attend a General Paediatric appointment in the preceding twelve months, 150 of whom had missed the appointment. This resulted in responses from 21 individuals. Five could not be contacted to schedule an interview, one withdrew due to constraints on their time, six were recruited into GH's study, and nine were recruited to the current study. However, one participant was not home at the scheduled interview time, leaving a total of eight. GH also recruited seven children and young people through this method.

During this phase potential participants were also approached in the reception area of the BCH outpatient department where families were waiting to see the General Paediatric consultants. The researchers discussed the purpose and nature of the research with parents, distributed information sheets, and collected contact details for parents interested in participating. These people were contacted after at least 24 hours, to allow time to consider participation. Confirmation of recruitment and interview arrangements were then discussed by telephone. This approach resulted in recruitment of three individuals to this study, one parent and three young people to GH's study, plus eleven who provided contact details but could not be reached by telephone or who ultimately decided not to take part.

### Recruitment phase two – outreach clinics

A further 120 letters were sent four months later, this time specifically targeting parents who had most recently attended one of the two community-based clinics. These letters were identical to the letters used in phase one, except a change in the description of the location of their care. Sixty families from each clinic were contacted. Two responses were received from parents attending the outreach clinic at Wychall children’s centre, one of whom was recruited to this study and one to GH’s study. A further four replies were received from parents affiliated with the outreach clinic at Greet health centre, again one of whom was allocated to this study. Two were interviewed by GH and one was thanked but declined an interview as data saturation had been reached for this cohort of parents. One young person from Wychall and two from Greet were recruited by GH.

**Table 6. Methods of recruitment and number of adult participants recruited.**

	Not interviewed <sup>a</sup>	Recruited to this study	Recruited to GH’s study
<b>Primary recruitment strategies</b>			
<i>Phase one – main hospital</i>			
300 letters (150 non-attenders)	7	8	6
In person	11	3	1
<i>Phase two – outreach clinics</i>			
60 letters (Wychall)	0	1	1
60 letters (Greet)	1	1	2
In person (Wychall)	4	4	2
In person (Greet)	7	5	1
<i>Sub-total</i>	<b>30</b>	<b>22</b>	<b>13</b>
<b>Additional recruitment strategies targeting non-attending parents</b>			
<i>Phase three</i>			
150 letters to non-attending parents	3	0	-
<i>Phase four</i>			
31 ‘snowball’ sampling letters to parents already interviewed	0	0	-
<i>Phase five</i>			
80 letters to GP managers distributing posters & stickers	0	0	-
<i>Phase six</i>			
66 letters to non-attending parents in the preceding month	4	0	-
<b>Total</b>	<b>39</b>	<b>22</b>	<b>13</b>

<sup>a</sup> Individuals who made contact about the study or provided contact details, but could not be reached to schedule an interview, declined to participate, were unsuitable for participation, or who were no longer needed due to data saturation

Face-to-face recruitment in the manner described above acquired a further four parents from the Wychall clinic, and five from the Greet clinic. Additionally, three adults were recruited by GH in this way (two at Wychall, one at Greet), as well as two young people at Wychall and two at Greet. Eleven parents provided contact details but could not be contacted by telephone, were unavailable for interview, or chose to decline participation (four at Wychall, seven at Greet). Parents recruited in person in both phase one and phase two were usually allocated to the study of the researcher who had recruited them, so that the rapport developed during the initial approach could be maintained and built upon during the subsequent interview. However, there were a few instances where interviews were conducted with parents who had been recruited by GH, as a result of fairly distributing participants to both studies.

At the end of phase two, GH had reached data saturation after 13 parent interviews and no longer needed to recruit participants. Transcription and preliminary analysis of interviews conducted for this study on attendance showed that sufficient information had been collected from parents who had experience of attending clinics at the hospital and outreach sites, and who had missed some follow-up appointments. However, it was felt that the sample required data from parents who had experience of more 'problematic' non-attendance, as described by BCH clinicians. For example, cases where multiple or first appointments had been missed, or where non-attendance was a result of their own decision-making rather than circumstances outside of their control. Supplementary sampling strategies in phases three to five were therefore implemented with the aim of recruiting these 'non-attenders' who had knowingly missed at least one appointment without cancelling.

#### Recruitment phase three – letters to non-attending parents

In March 2012 letters were sent to 150 parents who had missed a first appointment or at least two follow-up appointments. These parameters were selected to represent 'problematic' non-attenders as described by healthcare professionals at BCH. These letters were amended from those used in phases one and two to highlight missed appointments as the focus of the research, and to combine the invitation letter and information sheet into one booklet style document. Ethical approval for this amendment was obtained. Three phone calls were generated in response to these letters, all of which indicated that the appointment mentioned in the invitation letter had occurred several years ago. This suggested a problem with the addresses selected from the hospital records, and no participants were recruited during this stage.

#### Recruitment phase four – snowball sampling for non-attending parents

Later in 2012, 31 letters were sent to individuals who had been interviewed for this or GH's study in the preceding year and for whom a postal address was available on file. The letter thanked them for their participation and requested that they pass on the enclosed information sheet if they were aware of anyone who had been referred to the General Paediatric service at BCH, but were unable or had chosen not to go to an appointment (see appendix 1.5). Interview data and conversations during recruitment suggested that existing interviewees knew families who had missed appointments, and had relatives or acquaintances who also received outpatient care at BCH. This was therefore seen as a simple and low-cost strategy through which non-attending parents could potentially be enlisted. One existing participant responded to request the findings of the research at the end of the study, but no other contacts were made or parents recruited.

#### Recruitment phase five – letters to GP practices with posters for non-attending parents

Following ethical approval of a second amendment to the recruiting methods for this study, two final intensive stages were conducted to try and recruit non-attending parents. First, letters were sent to the practice managers of 80 GP practices in four of the local Primary Care Trusts that referred children to BCH at the time of the study (see appendix 1.6). Six of the GP centres were known to have high 'did-not-attend' rates at BCH outpatient appointments in the year 2010-2011. The letters explained the purpose and nature of the research and requested that they use the enclosed poster (see appendix 1.6) and sticker sheets to advertise the study within their practice waiting areas. Both the poster and stickers highlighted the option to register interest in the study by sending a text message with the word 'research' to the researcher. This mailing led to a phone call from one assistant practice manager who was interested to learn more about the study. A useful conversation was conducted regarding management of non-attendance in primary care, but no other responses were received.

#### Recruitment phase six - personalised letters to non-attending parents

Finally, 66 targeted letters were sent in two batches in October and November of 2012 to parents of children who were known to have missed an appointment in the preceding month. The letters were personalised using 'Dear parent of [child's name]...' and specified the date that the appointment was missed (see appendix 1.7). It was hoped that this would reduce hesitation about admitting to non-attendance as it was explicitly stated in the invitation letter, with no negativity insinuated. By sending the letters as close to the occasion of non-attendance as possible, it was hoped that the reasons and

circumstances surrounding the missed appointment could still be salient and so encourage participation.

This mailing led to four phone calls in response. However, the parents who made contact were either unsuitable for recruitment or chose not to participate. Three of the parents had not received an appointment letter and so did not know about the appointment or the need to attend. These individuals were directed to the BCH appointments team if necessary. The fourth response was from a mother who did not speak English. The reason for the research invitation letter was explained to an adolescent daughter who acted as an interpreter for the parent. The family had chosen to miss the scheduled appointment because they had previously not received the medication they wanted for another child, but did not wish to take part in the research, even if a hospital interpreter was provided.

Thus, despite numerous and varied methods to recruit 'non-attenders', phases three to six were not successful in supplementing the earlier sample with parents of this type. The sample was therefore finalised after phases one and two. A total of 22 parents were recruited to the study and 39 more individuals were contacted but not ultimately interviewed.

#### **5.2.4 Data collection**

In-depth semi-structured interviews were carried out with the recruited parents. A key feature of these interviews is that they combine structure and flexibility (Legard, Keegan et al. 2003) such that the researcher can maintain control over the conversation and obtain data that will answer the research question (Willig 2008), while permitting interesting responses and unanticipated issues to be explored, and allowing the interviewee to address the topics in the manner and order most suited to them.

Interviews were conducted at a time and location selected by the participant. A range of settings was offered including a room at the hospital, at the university, at one of the outreach clinic locations (if they were recruited through one of these sites), or at the person's home. The majority of participants chose to have the interview at home, however three opted to come to the hospital and one was interviewed at the children's centre where the Wychall outreach clinic was held. Flexibility was also offered in terms of the time at which interviews could be carried out and many participants requested that the researcher visit in the early evening. The interviewees who attended the hospital and clinic setting were offered a reimbursement of their travel expenses and refreshments during the interview, but no other incentives or remunerations were offered for taking part in the study.



The average length of interview was approximately 37 minutes, ranging from 13 minutes in the shortest interview up to 60 minutes. Interviews were offered in languages other than English with the aid of a hospital-employed interpreter. However this was not taken up by any of the participants.

### The interview guide

An interview guide (see appendix 1.8) was developed containing open-ended questions designed to elicit key aspects of parents' views and experiences, and to explore these aspects in detail (Legard, Keegan et al. 2003). The guidance set out by Braun and Clarke (2013) was followed to ensure that questions were precise, singular, non-leading, non-assumptive, linguistically appropriate, and empathetic. Variations of the main topic guide were created for use with non-attending parents, and for those who were seen at one of the outreach clinics rather than the main hospital. The main differences in these alternative guides were that experiential questions were framed in terms of what events *would have been* like rather than what they *were* like for the non-attending participants, and to change the clinic setting mentioned for the outreach clinic interviewees. The overall topics and order of questions otherwise remained the same.

The interview guide was organised so that questions were presented in a logical order, beginning with the broadest issues and topics that were expected to be the least difficult and most engaging for the participants to talk about, such as the child's health condition. Later questions were clustered around the key topics necessary for answering the research objectives regarding barriers and facilitators to accessing services, and views and experiences of attending and missing appointments. Questions about non-attendance were preceded by a statement aimed at normalizing missed appointments by stating that "many children and families miss appointments for lots of different reasons" and that the purpose of these questions was to find about the factors that lead to appointments being missed. It was hoped that this would put parents more at ease in discussing non-attendance by presenting it as a common occurrence. A summary of the topics included in the interview guide is provided in table 7, in the order that they were usually presented to interviewees.

Prompts and probing questions were also included in the interview guide to assist the interviewer in obtaining detailed responses related to different aspects of the research topic. Additional follow-up questions to encourage elaboration, specifying questions to request more detailed explanations, and interpreting questions to check understanding of the participant's meaning (Kvale 1996) were used during the interview to facilitate generation of rich descriptions. A closing question, "Is there anything you would like to add?" was used to encourage interviewees to discuss topics important to them that hadn't already been covered, and to signal that the interview would soon be ending. The

extent to which questions in the interview guide could be easily comprehended was tested by reading statements aloud and questioning colleagues. The guide was then further tested and refined in the process of conducting the first few interviews with participants.

**Table 7. Topics included in the interview guide**

<ol style="list-style-type: none"><li>1. Information about their family (e.g. number and ages of children)</li><li>2. The child's health issue (e.g. symptoms, duration, seriousness)</li><li>3. Events that led to referral to the General Paediatric service</li><li>4. Communication with BCH regarding appointments</li><li>5. Waiting time for the appointments</li><li>6. Management and treatment of the child's condition</li><li>7. Number and frequency of appointments</li><li>8. Other experiences of care provided by BCH</li><li>9. Experiences of coming to the clinic setting for appointments</li><li>10. The child's attitude and behaviour regarding appointments</li><li>11. Views on the location of the hospital</li><li>12. Views on delivering care outside of the hospital in community settings</li><li>13. Views on care provided outside of normal working hours</li><li>14. Experiences of missing appointments</li><li>15. Beliefs about attending appointments</li><li>16. Potential reasons for missing appointments</li><li>17. Views on other families missing appointments</li><li>18. Views on how the hospital manages missed appointments</li></ol>
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### Conducting the interviews

On arrival for the interview, general small talk was made about the interviewee's neighbourhood or recent events to put the participant at ease and develop rapport. Prior to questioning, all interviewees gave written informed consent denoting their agreement to participate and completed a brief verbal demographic questionnaire intended to provide personal and social context for their responses. The interviews were then recorded on a portable digital audio recorder, which was placed on a table or surface between the interviewer and interviewee. Notes were taken during the interviews if necessary to facilitate remembering of key points to be probed or to give the interviewee time to gather their thoughts.

Several other strategies for strengthening the interviewer-interviewee relationship and for maintaining engagement were implemented. This included frequent eye contact and attentive gestures (e.g. nodding, smiling, and encouraging utterances), reassuring the participant throughout the interviewee that no responses were incorrect or 'silly', using an interested tone of voice and

open body language, being responsive to the tone and body language of the interviewee, permitting contemplative silences to allow the person to consider their views, and pacing the interview so that questions and responses later in the interview need not be rushed (Legard, Keegan et al. 2003).

In several cases although participation had been negotiated with one individual, interviews were conducted either with other family members present in the background or with deliberate contributions from the second parent in the household. If partners had more than minimal input to the interview, verbal consent for their participation and recording was sought. This occurred in four interviews. In one household (interview P13) both parents were present throughout the interview as it was apparent they both had a desire to share the difficulties they had experienced in managing their child's condition. This couple often repeated each other's phrases to indicate agreement, and checked their responses with their partner through frequent questions at the end of statements such as, "Didn't they?" and "Isn't she?" In this way they presented a united front throughout the interview, and supported or built upon the answers given by the other parent. In two interviews (P14 and P21) the second parent moved in and out of the interview area, contributing in response to direct questions from their spouse or when they picked up on an issue they wished to address, and in one interview (P11) the partner arrived at home part-way through the interview and contributed only selective comments that backed up the primary participant's statements. In 14 of the interviews there were children present for some or all of the recorded conversation. This reflected the fact that participation was negotiated around availability of individuals with parenting and often employment responsibilities, and that many of the interviews took place at people's homes in the early evening when children had arrived home from school. However it was not felt that the presence of children or other family members in the background significantly hindered the participants from expressing their full and honest views.

At the end of every interview the interviewee was thanked for their participation and given a study debriefing sheet, which described how and when the results of the study would be available to participants, and the researcher's contact information in case of subsequent queries. Many of the parents at this point spontaneously questioned the interviewer about the likely outcomes and impact of the study, or made hopeful remarks about the usefulness of their contribution and the progress of the research. As soon as possible after leaving the company of the participant, reflective notes on the interview tone, content and setting were recorded.

## 5.2.5 Data analysis

### Data management and transcription

The digitally recorded interview files were transferred to secure university computer servers for storage and deleted from the electronic device. The interviews were then transcribed verbatim by the interviewer or by one of three contracted transcribers, as the time for analysis was limited. Nonetheless, close familiarity with the data was ensured as the researcher listened back to each recording while checking and editing the returned transcript. Transcripts were anonymized by removing any personally identifiable information and allocating each interviewee a participant identification number which has subsequently been used in all aspects of data analysis and reporting.

### Thematic framework analysis

Data were analysed using a thematic framework approach as described by Ritchie and Spencer (1994) and elaborated by Ritchie, Spencer and O'Connor (2003). Theme-based analyses are systematic approaches for identifying, analysing and reporting patterns or themes across a dataset (Braun and Clarke 2013). They organise and describe data in rich detail, and facilitate in-depth exploration of participant accounts through the active interpretation of themes. Thematic analyses, of which the framework method is one type, are free of theoretical assumptions, meaning that epistemological positions and decisions about the type of analysis are explicitly determined by the researcher with reference to the research question, rather than imposed by the method (Braun and Clarke 2006). In order to achieve the research aim of identifying the wide range of factors that potentially influence attendance at appointments, this study required a generative data-driven approach rather than a prescriptive, top-down implementation of theoretical constructs. An inductive analysis of the meaning, experiences, and realities of participants was therefore conducted.

Themes were generated at a semantic level, meaning that although the analysis involved interpretation in terms of theorizing and generating explanations, no attempts were made to 'go beyond' what was explicitly said by the participants (Braun and Clarke 2006). That is, participant statements were taken as accurate representations of their perceptions and beliefs, and responses were not interpreted in terms of latent meanings or underlying conceptualizations (Braun and Clarke 2013).

The framework method involves data management techniques that facilitate in-depth analyses across large and diverse data sets. Central to the method is the use of a 'thematic framework' which organises and synthesises data into codes, categories, and sub-categories. This allows each preliminary theme to be displayed in a summarised chart, or matrix, where each column represents

an element within the theme, and each row represents an individual participant (for an example of a theme matrix see appendix 1.9). This approach ensures that analytical stages are carried out comprehensively, transparently, and rigorously (Ritchie, Spencer et al. 2003). The use of the matrix format encourages the researcher to look for patterns both between and within participants, and allows movement between different levels of interpretive abstraction while ensuring that strong links with original data are retained (Gale, Heath et al. 2013). The use of the framework method was selected as an organised approach to data analysis that assists with the creation of detailed and nuanced themes, and through which closeness to the original data is facilitated and readily demonstrated. The five stages of the thematic framework method are outlined in table 8, and the final thematic framework applied to the whole data set is presented in table 9.

**Table 8. Stages of the thematic framework method**

<i>Stages of the framework method<sup>a</sup></i>	<i>Description of processes within each stage</i>
1. Familiarization	Listening to interview recordings, reading interview notes, transcription, studying the data, making notes on initial ideas and recurring themes
2. Identifying a thematic framework	Developing a coding framework, applying it to a few transcripts, then refining the framework
3. Indexing	Systematically applying the coding framework to all of the transcripts so that data relevant to each potential theme are referenced under the same labels
4. Charting	Creating a chart for each potential theme with cases and codes represented in rows and columns, and summarised data entered into each 'cell' of the chart
5. Mapping and interpretation	Reviewing the charts to compare participant accounts, seek explanations for patterns in the data, and create a meaningful structure

<sup>a</sup> Adapted from Ritchie and Spencer (1994)

## 5.3 FINDINGS

### 5.3.1 Participant characteristics and experiences

The recruited parents were diverse in terms of ethnicity, the health conditions for which their children were seen by the General Paediatric service, and the ages of these children. These and other key socio-demographic and clinical characteristics of the sample are presented in table 10.

**Table 9. Thematic framework applied to the whole data set**

<b>1. The Family and Daily Life</b>
a. Family information
b. Daily life and relationships
c. Family health issues
d. Non-health issues
<b>2. Parenting</b>
a. Views on being a parent
b. Attitude to the child, their health and care
<b>3. The health condition</b>
a. The 'story' of the condition
b. Symptoms
c. Course or timeline
d. Impact or consequences
e. Perceived causes
f. Knowing what the condition is
g. Views and attitudes to condition
h. Child's attitude to the condition
<b>4. Managing the condition</b>
a. Managing the condition
b. Medications
c. Advice from HCPs
d. Relationships with schools
e. Feelings about managing the condition
f. Child's attitude to managing the condition
<b>5. Healthcare</b>
a. History of care
b. Multiplicity of care
c. Tests and investigations
d. Communication
e. Relationships with HCPs
f. GP care
g. Emergency care
h. Inpatient care
i. Views and attitudes to healthcare
j. Child's attitude to healthcare
<b>6. Managing appointments</b>
a. Managing appointments
b. Communication about appointments
c. Waiting times
d. Views on appointments and attendance
e. Missing appointments – experiences & reasons
f. Hospital management of attendance
<b>7. Visiting the clinic</b>
a. Visiting the clinic
b. Travel
c. Parking
d. Place
e. Time of the appointment
f. Waiting in the clinic
g. Views and attitudes to clinic visits
h. Child's attitude to clinic visits
<b>8. Community-based care</b>
a. Views & experiences of community-based care

The majority of interviewees were female, but three fathers were interviewed and a further three fathers were present as secondary participants. Socio-economic status was not formally assessed but interviews took place at homes in various postcode areas and neighbourhoods perceived by the researcher to range from fairly deprived to very affluent. There was also a mix of single and two-parent households represented, and participants had varying numbers and ages of children for whom they were responsible.

The health issues for which children were referred to the General Paediatric clinic included a range of short and long term conditions, at varying stages of diagnosis and treatment (see table 10). Some children were seen in General Paediatrics for acute issues while simultaneously living with complex chronic conditions. For example, one child who attended two appointments for a water infection was also receiving care from another BCH service for Phenylketonuria (PKU), a serious condition which can cause brain damage if not managed appropriately. Families' experiences of receiving care from multiple services, both within and outside of BCH, will be addressed in the findings where appropriate.

There was variation across the sample with regards to the child's stage of treatment and type of relationship with the service. For example, some families were new to the service and awaiting investigation and diagnosis, others were receiving a limited number of check-up appointments following advice and treatment, and some were seen over longer periods for ongoing monitoring of chronic or complex conditions, with a few having longstanding "regular appointments". All but one parent was seen by hospital consultants, or medical registrars supervised by a consultant. Participant P10 was seen by the General Paediatric clinical nurse specialist for allergy testing, but also had extensive experience of consultant-led appointments for the same child within the respiratory service for severe asthma.

All of the parents interviewed had experience of attending at least one General Paediatric appointment. However, fifteen of the interviewees also reported having *not* gone to an appointment for this service at BCH on at least one occasion, whether by choice or through error. This included four parents whose children were too unwell on the day of the appointment to attend, three of whom called to cancel on the day in question, and one of whom attempted to call but was unable to get through. This latter instance would certainly have been recorded by the hospital as a "did not attend", however the other instances of calling on the day may have been noted as a cancellation rather than non-attendance if this was adequately communicated and recorded within the hospital. A further two interviewees described occasions when appointments had been missed because the child had been unwell and admitted to the children's hospital through the emergency department.

**Table 10. Participant characteristics**

Parent ID number	Gender	Ethnicity	Clinic <sup>a</sup>	Age of child <sup>b</sup>	Child's health condition <sup>c</sup>
P01	Male	South Asian	Main Hospital	2	Fits
P02	Female	South Asian	Main Hospital	7	Seizures ( <i>also has developmental delay</i> )
P03	Female	White other	Main Hospital	3	Not putting on weight
P04	Female	White British	Main Hospital	14	Vitamin deficiency & joint pain
P05	Female	White British	Main Hospital	9	Knee trouble after car accident
P06	Female	White British	Main Hospital	8	Urinary tract infection ( <i>also has phenylketonuria</i> )
P07	Female	White British	Main Hospital	14	Coeliac disease
P08	Female	White British	Main Hospital	6	Bowel problems
P09	Female	White British	Main Hospital	12	Oral allergy syndrome, cold angioedema, asthma
P10	Female	White British	Main Hospital	5	Possible allergies ( <i>also has severe asthma</i> )
P11	Female ( <i>child's father also present</i> )	South Asian	Main Hospital	2	Recurring viral infections, scarlet fever
P12	Female	White British	Wychall outreach	4	Kleefstra syndrome, epilepsy
P13	Female ( <i>child's father also present</i> )	White British	Wychall outreach	11 months	Bowel & feeding problems
P14	Male ( <i>child's mother also present</i> )	South Asian	Greet outreach	2	Fainting problem
P15	Female	Black British	Greet outreach	10	Epilepsy
P16	Female	South Asian	Greet outreach	11	Vitamin deficiency & diarrhoea
P17	Female	South Asian	Greet outreach	10 months	Wheat allergy
P18	Female	South Asian	Greet outreach	6	Overweight & breathing problem
P19	Male	White British	Wychall outreach	11	Recurring kidney infections
P20	Female	White British	Wychall outreach	4	Epilepsy
P21	Female ( <i>child's father also present</i> )	Black British	Wychall outreach	5	Epilepsy
P22	Female	White British	Greet outreach	13	Undiagnosed problems with heart & fatigue

<sup>a</sup> Location of recruitment and setting of last appointment attended

<sup>b</sup> Age at the time of interview

<sup>c</sup> Condition for which the child was referred to the General Paediatric service, as described by the interviewee



In addition to issues related to the child's health status, non-attendance also occurred due to administrative errors that had resulted in parents not receiving appointment letters. This was reported by two participants as a reason for missing a BCH General Paediatric appointment, though many interviewees also mentioned this as a problem at other NHS organisations and services. Other reasons for unintentionally missing appointments included forgetting due to the busy rush of daily life, and confusion or mis-remembering of the appointment date.

Four interviewees described making a conscious decision not to attend appointments. For one parent this was because of other responsibilities in her life that she had to manage alongside the child's healthcare appointments, including providing full time care for her own father. For another parent trying to get her 14 year-old daughter to attend the appointment would have been "*too stressful*" as her child was "*in a foul mood*" (P07). Finally, two parents discussed having missed appointments, possibly on more than one occasion, as the given appointment times were felt to be inconvenient for them.

Thus, although there were difficulties in recruiting 'problematic non-attenders' to the study, a thorough investigation of missed appointments was still possible given the wide range of non-attendance reasons, motivations and experiences within the sample. These experiences may explain and be explained by the findings of the thematic analysis, as well as providing context for parents' views.

### **5.3.2 Findings of the thematic framework analysis**

The thematic framework analysis generated six themes: 1.) Planning and managing appointments; 2.) Experience of attending appointments; 3.) Evaluations of healthcare; 4.) Perceived seriousness of the child's health condition; 5.) Controlling the health condition; and 6.) Responsibilities as a parent and as a health service user. Each of these themes will be described in detail in the following sections with illustrative quotes from the data supporting the findings. Further interpretation, explanation and theorizing about the factors influencing attendance will be reported in the discussion section of this chapter.

#### **5.3.2.1 Theme one: Planning and managing appointments**

Every interview included some discussion of how participants managed the planning and organization of appointments for their children. These discussions covered views and experiences of handling appointment letters and reminders; remembering scheduled appointments; fitting clinic visits around other aspects of daily life; and calling the hospital to reschedule appointments or inform the service of an unplanned non-attendance. Much of this talk highlighted the ways in which

these issues impacted on parents' *ability* to attend, thus representing potential barriers and facilitators of attendance. Reported barriers were not merely perceived difficulties of going to appointments, but phenomena that interviewees believed had the power to entirely prevent attendance. Facilitators on the other hand were factors that made it easier or more likely for families to attend.

#### Appointment letters and reminders

Most participants reported no problems with written communication from the hospital. Parents observed that appointment letters were "*clear and easy to understand*" (P21), "*very thorough*" (P13), and arrived "*quickly*" (P03) and reliably, or "*on a regular basis*" (P11). However, a significant minority of interviewees had experienced problems with letters from the hospital, which in some cases had prevented attendance at the scheduled appointment.

#### Administrative errors

Three participants explained that on previous occasions BCH appointments had been missed because they had not received an appointment letter. Three further interviewees reported similar problems with letters from other hospitals. In two cases this was blamed on the family's local postal service, but three parents cited the problem as stemming from the hospital having the wrong address on file.

*"There was a mix-up with the addresses, my ex-wife moved address... and they didn't change the address at the hospital. Everywhere else but at the Children's. So they sent a letter out for an appointment, which should have been last month, which obviously we never got. So they actually wrote her off."* (P19)

In this instance, the error in the addressing of the appointment letter not only obstructed attendance at one particular appointment, but led to the child being removed from the clinic list meaning that future alternative appointments were also jeopardised. Furthermore, one parent mentioned that poor typing of an address had resulted in a letter being delivered incorrectly and their family's privacy being violated.

*"They've sent a letter and it was misaddressed, and there were lots of misspellings and things, and it's gone to the neighbour and the neighbour's opened it. So they've obviously read all the contents, and that's a problem that we're pursuing at the moment."* (P03)

#### Timing of appointment letters

Another problem with appointment letters was receiving them too close to the time of the scheduled appointment to provide sufficient notice for planning attendance, or indeed receiving the letter on or

after the date of the appointment, which was reported by two interviewees. In either case attendance was made impossible or extremely difficult.

*"I've had appointments in the past that had gone. I've had letters at short notice, then again I've just made it... I've had the appointments at just two days notice." (P02)*

Receiving letters far in advance of scheduled appointments was noted far more frequently. Some parents observed that appointment letters were sent almost immediately following a referral or prior appointment, and perceived this to be a positive occurrence.

*"I've always had either an appointment date there and then or they've said we'll send you one in the next couple of weeks, which they always do." (P08)*

Three interviewees remarked that receiving the appointment letter early facilitated attendance as having "*plenty of notice*" (P19) meant that they had "*time to prepare*" (P15) for going to the hospital. One participant commenting on appointment letters sent by the BCH dietetic service was emphatic that the hospital provided sufficient notice to plan for clinic visits and so lack of time could be no excuse for non-attendance.

*"Whoever says that they couldn't make it to the appointment because they didn't give them enough time, that is – I'm not going to swear - that's bull. Because I've had an appointment for October. October! What are we in, August? And I got it in April! So six months in advance I know that time." (P06)*

Yet receiving appointment dates this far in advance was not universally perceived to be beneficial. Six parents noted problems with long notice periods, including losing the appointment letter, forgetting about the appointment, and forgetting details about the appointment such as the name of the consultant. For example, parent P05 discussed difficulties remembering appointments for herself or her child when they were sent one or two months ahead, and parent P12 fully anticipated losing hospital letters.

*"I have missed a couple of appointments for myself with things like that, because I've had the letter like a month before." (P05)*

*"I've got an appointment for next year, but I haven't got a calendar yet for next year... and I know I'll lose the letter that they sent me." (P12)*

Hence, receiving letters too soon was actually felt to impede some parents. However, all participants who talked about the challenges of remembering distant appointments also recommended the use of reminders from the hospital to resolve these issues.

### Using appointment letters as organizing and negotiating tools

Not only did letters provide parents with necessary information about where, when and with whom their child's General Paediatric appointment would be, they were also used in two other ways by participants to facilitate attendance at appointments. First, interviewees described using notifications of appointments as part of their appointment remembering strategy. Three participants spoke about keeping letters in a particular place so that they could be checked regularly or nearer the appointment time. This was especially important when children had many appointments scheduled, or when appointment dates had been rearranged by the hospital.

*"I keep all the letters and then I'll go through the letters and check the ones that have been cancelled. I keep them all together and then look, 'Oh that one was cancelled so I've got to go this week.'" (P18)*

*"Sometimes you do get a letter a couple of months before the appointment. And then I stick it on the fridge... I'm constantly looking on the fridge, 'I know I've definitely got something on such and such date, let me check.'" (P05)*

Secondly, and perhaps more unexpectedly, some parents also discussed using appointment letters as negotiating tools to obtain 'permission' to attend appointments from schools or employers, and to back up attendance at the hospital when reception systems failed to retrieve records of scheduled appointments.

Schools: *"They don't like it. So to cover your back, you always need to give a medical note or the letter from the hospital, because you don't want the attendance officer coming round to your house saying you've missed so much." (P11)*

Employers: *"No problems there [with child's school] at all. One telephone call, they don't even ask to see letters. When it comes to employers, 'Oh can you prove it?' I do take the letter." (P21, father)*

Hospital: *"If they haven't got it [the appointment] on the system or can't find it, you have to hang around and wait. Because that's what happened to me once with [child]. Didn't have appointment time and I forgot my letter, so I had to hang around and wait." (P20)*

### Perceptions of appointment reminders

Participants found appointment reminders sent by BCH to be extremely valuable for several reasons. As aforementioned, appointments scheduled far in advance were difficult to remember so parents reported relying on the delivery of reminders to prompt their memory of the appointment and to start planning the visit.

*"When I see the reminder I think, 'Okay', so I know that it's more recent in my head, so I remember. Because you get the letters how much months before and then you get a reminder like a week before, so you've got time to think, 'Okay yeah, we've got that coming up.'" (P15)*

Reminder letters were also an important source of specific appointment information when initial letters were misplaced.

*“You always get a reminder about a week before. You always get a reminder letter basically just in case you lose the original letter, which I have done a few times.” (P08)*

Most interviewees had experience of receiving reminders by post, but there were mixed views regarding the provision of reminders by other means. Three participants advocated sending reminders by text message or email. These methods had the benefits of alerting parents to appointments even when letters went astray in the post and were perceived by two parents to be less wasteful.

*“They write the letter. But I haven’t got time for letters, I don’t want them, that’s a waste of paper. That’s a waste of resources. I’ve got it on my phone, here it is.” (P21, father)*

In contrast, participant P19 queried whether families would find text messages useful.

*“You can send text messages, you can send emails. People aren’t going to read them. You know how many people look at their texts?... When I had my appointment that I had last Friday, I looked at it once and that was it. It was on my phone for a week and a half. I never looked at it again... Stuff like that it doesn’t help people.” (P19)*

This interviewee instead found self-administered reminders useful for facilitating attendance by preventing forgetting.

One interviewee perceived reminders to come directly from the consultant herself, with whom she had a positive relationship. Reminders were consequently seen as a sign of the healthcare professional supporting and caring for the family.

*“She’s very good because she says to me, ‘Now I’ll see you in six months.’ And in six months’ time I will receive a letter a week beforehand to remind me that your appointment with [consultant] is on this day. So she never forgets... That’s one good thing about her she always reminds you beforehand.”(P18)*

Reminders therefore led to even greater likelihood of attendance for this parent, as she appreciated the perceived gesture from the consultant and intended to reciprocate this thoughtfulness through timely attendance.

Only one participant made remarks suggesting that reminders were not perceived as valuable. Parent P13 described receiving reminders one week before appointments, but stated, *“I don’t know why that’s necessary”* (P13). This interviewee clearly thought that the original appointment letter was sufficient, perhaps because the appointments were tremendously important to them for controlling their child’s painful condition and so were not easily forgotten. Yet, the same parent

reported previously missing an appointment due to remembering the wrong date, which could potentially have been prevented by the delivery of a reminder.

### Strategies for remembering appointments

Just two participants disclosed that remembering appointments was “*not easy*” (P05) or “*really hard*” (P02). Nonetheless, it was commonly acknowledged that personal strategies for remembering were essential for preventing forgetting and non-attendance. Findings described in the previous section highlight that parents relied on reminders from the hospital and kept appointment letters in designated places so that they could be checked at regular intervals. A range of other methods were discussed by participants, the most common of which was writing the appointment details on a calendar or diary. This was perceived to be an effective way of remembering and preventing non-attendance.

**Interviewer:** “*Have any of the children missed an appointment at the hospital?*”

**Parent:** “*No, no.*”

**Interviewer:** “*And why is that?*”

**Parent:** “*Well, I write it in my diary.*” (P09)

However, one interviewee explained that with “*busy life going on with the children*” (P15) she sometimes failed to write the appointment in her diary, or failed to check the diary, meaning that she was somewhat reliant on hospital reminder letters to prompt her remembering.

This calendar approach seemed to fit well with participants’ usual strategies for managing household events, meaning that it was perhaps one of the most straightforward to implement successfully.

*“Everything’s on the calendar, every single doctor’s appointment, what we’re doing, what they’re doing at school... Everything’s written down. And then obviously you turn it over and look at August, look what day you’re on and remember.”* (P06)

Five interviewees also discussed setting alarms and electronic reminders on mobile phones or computers. This method was advantageous in that parents had control over the timing and frequency of personal reminders.

*“As soon as I get one I put it straight on my phone diary. I can then set it for the day before, two hours, ten hours, whatever I want and I can have multiple recurrence of that alarm.”* (P19)

Finally, one parent who found remembering appointment dates very difficult reported that she merely remembered the month or approximate timing of the appointment then when this period approached she telephoned the hospital to check the specific appointment details.

*“I know there’s an appointment somewhere along the line in April and in October, so just near to that time I’ll ring up the hospital just to find out, okay [child]’s got an appointment with the paediatrician, ring up and just find out when it is.” (P02)*

Some other participants described either deliberately remembering just the appointment month and checking near the time, or calling the hospital to confirm appointments details, but parent P02 was the only interviewee who combined both aspects in a deliberate strategy to remember appointments.

#### Fitting appointments around other aspects of the family’s daily life

A major concern for participants planning paediatric outpatient appointments was how to arrange the clinic visit to fit in with the life and commitments of the entire family. Some aspects of personal and family life were recognized as potential barriers to attending the hospital at the given appointment time. These included taking time off work, taking the child out of school, care for other children, and other family members’ healthcare needs. The ways in which participants handled each of these barriers depended partly on the availability of practical help from partners and wider family members, and partly on their perceptions of the seriousness of the child’s condition and the importance of the hospital appointment.

Table 11 displays characteristics of interviewees and their families to provide context for the following findings, as not all parents were in employment, had other children to care for, or had other healthcare issues to manage, and not all children were yet old enough to attend school. Potential barriers were therefore experienced by some families and not others. The table also shows whether children were cared for by one or two parents, as this was important for how participants dealt with these issues.

#### Taking time away from work

In this sample of 22 participants, nine reported being in some form of employment (see table 11). All but two of these parents talked about difficulties in attending appointments due to the need to take time away from work. Barriers included problems with being granted time off by employers, and real or perceived limitations on the number of days off that were acceptable. For the two interviewees who were self-employed appointments were not overtly problematic, and part-time workers had more opportunities to accommodate children’s hospital visits. However, all participants who were employed in full-time jobs commented on the challenges of managing appointments alongside work commitments.

**Table 11. Participants' employment status and family circumstances**

Participant ID number	Participant's employment	Whether child of school age	Number of <u>additional</u> dependent children <sup>a</sup>	Other family health issues <sup>b</sup>	Who cares for the children
P01	-	x	1	P	Two parents
P02	-	✓	4	Ch & Ch	Two parents
P03	Part-time	x	1	Ch	Two parents
P04	-	✓	2	-	Single parent
P05	-	✓	-	P	Single parent
P06	Part-time	✓	-	P	Single parent
P07	-	✓	2	P & Ch	Single parent
P08	-	✓	1	P & Ch	Two parents
P09	Part-time	✓	2	P & Ch & Ch	Split care <sup>c</sup>
P10	-	✓	2	-	Two parents
P11	Part-time	x	2	Ch	Two parents
P12	Full-time	✓	1	-	Two parents
P13	Self-employed	x	1	-	Two parents
P14	-	x	3	P	Two parents
P15	-	✓	3	-	Single parent
P16	-	✓	1	-	Two parents
P17	-	x	1	-	Two parents
P18	-	✓	1	-	Single parent
P19	Self-employed	✓	2	P	Split care <sup>c</sup>
P20	-	✓	1	P & Ch	Two parents
P21	Full-time	✓	3	P	Two parents
P22	Full-time	✓	2	-	Single parent

<sup>a</sup> Children under the age of 16 who live with the participant, not including the child who is the main subject of the interview

<sup>b</sup> Ongoing health issues requiring specialist healthcare; P = participant, Ch = another child in the family

<sup>c</sup> Care for the children divided between two separated parents

With regards to obtaining approval for time off work, one participant noted that his employer had been “so understanding” (P13, father) and supportive of him attending appointments, but another gave a troubling account of difficulties negotiating time off from his full-time job.

*“I do have problems because the minute you say you have to do this they want, ‘Can't another member of the family?’... I got an appointment for my daughter, ‘Well, you should've booked it.’ Well most of the time I'll end up losing pay over it... It can be very frustrating, that sometimes I have to lie, sometimes I have to say I'm not well. Just to be able to take her to the hospital. I find that not very compromising.” (P21, father)*

More commonly, interviewees mentioned concerns about taking ‘too much’ time off work to attend appointments, stating they had “still got to work” (P22) or “couldn't keep having time off work” (P12). This perceived restriction was more likely to be problematic when children had many or frequent appointments.



Hospital appointments during parents' hours of work were thus challenging for many participants who were in employment. Some parents resolved this issue by having their partner or a family member attend the appointment with the child rather than attend it themselves. However, this was not possible for all interviewees, and was believed to have its own disadvantages as the parent would not receive information directly from the healthcare professional and would have less influence over decisions about their child's healthcare. For example, participant P22 described her mother taking her son for his first appointment at another hospital, but attending the next appointment herself so that she could more easily pursue information about his condition.

*"My mum took him up for the blood test because I've still got to work... The second one I done it because I thought to myself, 'This is getting serious now' and I wanted answers, where my mum isn't as forward as me. I think as a parent you can be a little bit more pushy, can't you?" (P22)*

This quotation demonstrates that the decision to prioritise attendance at the child's appointment over work commitments was often dependent on the perceived seriousness of the child's condition or perceived importance of the appointment. This was further illustrated by the father in interview P13 who noted that he had taken so much time off for managing his child's condition and going to the hospital that he *"could've easily lost [his] job"* (P13, father), but attended every appointment regardless. This interviewee's child had a severe, persistent, and painful condition and it was important to this father to be able to attend appointments with his wife not only to assist her in managing the child, but to *"hear what they [the consultants] have got to say"* (P13).

#### Taking the child out of school

Six participants had children with health conditions who were too young to attend school (though four of these also had older children who may have had hospital appointments with different services). The remaining 16 interviewees had to make decisions about whether the child should miss time in school to attend General Paediatric appointments. Although some schools were said to *"moan"* (P05) about the child taking too much time off because of illness, injury or visits to the hospital, most participants reported that schools were either supportive or simply had to accept the child's absence.

*"They've got no choice to be, but yeah they're fine. They know it's important."* (P10)

Nonetheless, parents were keen that their children didn't miss time in class because of potential effects on their education, and because often children were opposed to missing school.

*“They're missing out a lot, especially if they go on a regular basis to the hospital... It all counts at the end of the day... Worry, ‘Oh, they've missed a numeracy lesson’ or their literacy which is quite important.” (P11)*

*“She doesn't like missing lessons... If she has to come out of school she doesn't like going in late or leaving early.” (P09)*

Concern about the child missing school was therefore something of a barrier to attending appointments during standard clinic hours. Again, the decision to permit the child to miss school or not was often made or justified according to the perceived seriousness of the child's condition or necessity of the appointment.

*“The school are saying to me that she's going to these appointments and she's missing half a day, and I'm like well it's a medical reason, it's not as though I'm taking her on holiday or something.” (P18)*

#### Care for other children

A third potential barrier of daily life that could prohibit attendance was the need for participants to provide care for other children in their family, especially if the appointment time was at the beginning or end of the school day. This was only a minor problem for interviewees with partners who shared childcare responsibilities or who had relatives that were able to assist, like participants P21 and P10.

*“One of us would have to go and the other would stay at home and cook, and do homework and the rest.” (P21)*

*“My daughter's usually at school and my mum will pick her up for me.” (P10)*

However, for interviewees without these support structures, planning attendance was difficult. Parents either had to attend during the day meaning that the child with the condition missed school, or had to attend after school hours meaning that all children were brought to the appointment. The former option was troubling as parents had to ensure that they were back in time to collect children from their schools or nurseries, which was made more difficult by long and unpredictable waiting times.

*“She had to have a blood test and... when we got our number there was about twenty people in front of us. And I said, ‘I can only stay here for about 30-40 minutes because I've got to get back to school to pick up the little one from nursery.’ I think we waited about 35, 40 minutes and just as we was about to go I think our number was just coming up.” (P07)*

Yet the latter option was perhaps even more stressful due to the challenges of entertaining several children before and during consultations. Participant P07 chose to arrange appointments during school hours so as to avoid bringing all three of her daughters to the hospital because this was “very stressful” (P07).

*"I can deal with it if it's in the morning even though I realise that she's going to miss school, but obviously her health's more important. But if it's in the afternoon I'm just dreading it all day." (P07)*

This parent explicitly chose to prioritise the avoidance of a stressful and unmanageable experience over potential effects on the child's education, and justified this by invoking the importance of the appointment for the child's wellbeing.

#### Other family members' healthcare needs

Thirteen participants noted in their interviews that they or one of their other children also had ongoing health issues requiring appointments with specialist services. This meant that sometimes difficulties in managing the child's condition and attending appointments were intensified by parents' own poor health, having to manage other children's illnesses, or conflicting healthcare appointments. These issues were less pronounced in families where two adults were available to take children to appointments, but still affected these parents' healthcare decisions. For example, participant P21 reported that she had had "so many appointments" and "so much time off" (P21) due to her own anaemia that she could no longer afford time away from work for her child's appointments and her partner took the child for all clinic visits instead. Yet the child's father also had diabetes and was hospitalised on one occasion, which necessitated calling to cancel the child's outpatient appointment at the last minute.

*"There's one time we had to reschedule her appointment because her dad was in hospital, so another emergency event that's so hard that would make you cancel... I called them and told them that I couldn't take [child] in because the dad is in hospital." (P21)*

#### Telephoning the hospital

The final obstacles reported by interviewees were difficulties related to making telephone calls to the hospital. These issues seemed to be more problematic for parents who had the telephone number for the general appointment line for the hospital rather than those who could call the secretary of their child's consultant directly. Two interviewees noted that they had tried to call the general appointment line, but couldn't 'get through.' Parent P03 found that her call went unanswered and she couldn't leave a message, and parent P09 commented that it was difficult to find time to call during hours that the telephone line was staffed.

*"I've tried to phone up because a child was ill and tried to cancel an appointment, and then found you can't get through which is a problem. Because obviously they've got only a limited number of phones and you can't leave a message. So then by the time you've phoned up you're either at your appointment or after your appointment time, in which case it's too late and they say, 'Oh why didn't you phone up earlier?'" (P03)*

*"I've only tried once and it wasn't all that easy to be honest, it can be quite difficult for me to be in at the same time as there's anybody actually answering the phone at the other end... They don't have any published times so it's just trial and error really." (P09)*

The latter quotation highlights that parents who are employed or have other commitments may find it difficult to communicate with the hospital to arrange suitable appointment times. If this problem occurred alongside a short appointment notice period, this could easily lead to missed appointments. Moreover, the problem of telephone calls being unanswered meant that participant P03 was unable to inform the service of an impending non-attendance, and so would have been marked as 'did-not-attend' on her child's hospital record rather than a cancellation. Not only is this frustrating for parents, but it may also discourage attempts to communicate with the hospital about potential non-attendances on future occasions. An additional barrier for some families might be verbal communication difficulties either due to language issues or hearing problems, both of which were experienced by participant P14.

*"Depends on the accent. We have language problems because there are some phones we can't understand them. They explain us, we taking time. But they helpful. Not comfortable to speak, but still we can manage." (P14)*

There was also discussion in the interviews about parents calling the hospital after a missed appointment had occurred. Some interviewees spoke about telephoning to explain why they had not attended or to "apologise" (P13, P20). Six participants described making telephone calls to reschedule the missed appointment. Several of these parents were apprehensive about the possible response from the hospital, fearing they might be reprimanded.

*"I [thought], 'They're going to make me feel dreadful now', because I missed it." (P07)*

However, all accounts indicated that hospital staff were "fine" (P05, P20) and readily assisted parents in making new appointments.

*"They just said, 'We'll get you another letter out in the post, we'll hand this to the relevant department', so it was alright. They didn't make me feel bad or anything like that... They were ok about it. They said, 'These things happen.'" (P07)*

This response by hospital staff may be beneficial in encouraging future communication and attendance by building positive relationships with the hospital. However, it could also be argued that this response might lead to future non-attendance as parents perceive it to be 'easy' to reschedule missed appointments. The effect is likely to be dependent on the individual and the particular circumstances of the future occasion.

### Theme summary

This theme has highlighted factors that affected participants' *ability* to attend either by entirely preventing attendance or significantly impeding or facilitating attendance. Attending appointments was inhibited by issues affecting knowledge about the visit, such as not receiving the appointment letter. In these cases it was simply not possible that families could go to the appointment. Other factors were presented as prohibitive barriers, including difficulties taking time off work, impacts on schooling, childcare or other family members' healthcare needs. However, given that these issues were generally known beforehand it is reasonable to expect that these should result in rescheduling of appointments rather than non-attendance. Yet if letters were received at the last minute or telephone calls to the hospital were unanswered, these issues could in fact result in missed appointments. The above factors decreased participants' ability to attend, but factors increasing ability were also mentioned including sufficient time for planning hospital visits, appointment reminders and remembering strategies to reduce forgetting, and letters used to negotiate with employers and schools. The likelihood of attending was increased through these means.

#### **5.3.2.2 Theme two: The experience of attending appointments**

All participants gave accounts of the process and experience of attending children's outpatient appointments. These descriptions encompassed many aspects of attendance, including travelling to the hospital, perceptions of the clinic environment, waiting in the reception area, and managing children before and during the consultation. Interviewees commented on the factors that made attending more or less difficult, and more or less stressful for families.

### Travelling to the clinic

Participants' journeys to Birmingham Children's Hospital varied in distance, travel time and modes of transport. The closest family to BCH lived approximately 1.5 miles away, while the farthest was required to travel approximately 9.5 miles. Interviewees reported travelling by car, bus and train, often with some walking between transport connections. While some parents described a predominant mode of travel, many families used different methods or combinations of methods depending on the circumstances. Although some participants were recruited via outreach clinics, all but one interviewee (P17) also had experience of travelling to the main hospital site for General Paediatric appointments or other services. Two main aspects of travel were noted by participants as contributing to the stress or difficulty of attending. These were the complexity of the journey to the hospital, and the financial cost associated with getting there.

### Complexity of the journey

Interviewee's accounts indicated that issues with travel were not related simply to journey time or distance. Rather, perceived travel difficulty depended on the complexity of the journey, including the number of stages of travel and whether or not the journey was 'direct'. Eight interviewees described their journeys as "easy" (P07, P08, P09), "fine" (P10), "not hard" (P01, P06) and "not a problem" (P03, P04) because the trip involved only one bus rather than many, or because their chosen method of transport took them "straight there" (P10).

*"It's not really hard [to get to BCH]. We're just one bus route. It's better to come to this hospital than to go to [other hospital] because if you go [other hospital] we catch two buses."* (P01)

*"It's not a problem because it's directly into the city centre... It's much easier to get to than most of the other hospitals."* (P03)

As noted in the second quotation above, the 'directness' of participants' journeys was thought to be facilitated by the city-centre location of the hospital. This was especially true for those travelling by public transport, as the city was perceived to have good transport links. This was supported by participant P05 who stated that "it's one bus to the Children's [Hospital]... which isn't too bad" but travelling to her 'local' hospital in an outer area of the city took "a good hour" because of the circuitous route of the bus, despite being a "straight run" in the car (P05).

Parents who travelled to hospital appointments by car also sometimes found journeys to be complex. In particular it should be noted that interviewees who were in employment and those who had children of school age often travelled to appointments via their place of work and the child's school, and also completed the same trip in reverse on the way back, meaning that journeys were especially complicated and tiring as noted in this excerpt.

*"I'd have to travel all the way across the city to take her back to school... and then I worked on the opposite side of the city so I'd go from the same side, to the middle of the city, then all the way back south side, and then all the way over north. So it was pretty exhausting."* (P12)

In addition to challenges associated with complex journeys, it was apparent from the interview data that travelling to the hospital was made more or less stressful depending on the number, ages and behaviour of children attending with the parent. For example, interviewee P06 said that travelling by bus wasn't difficult because her daughter was "well behaved, she plays with her DS [games console] or whatever" (P06). In contrast, interviewee P20 noted that travelling by train with younger children was hard "when you've got a fairly big buggy to get on" and the secondary participant in interview P13 observed that his infant daughter "won't sit in the car and travel easily, she doesn't like being restricted" (P13, father), making long journeys to the hospital difficult.

### Cost of the journey

Several participants noted the expense associated with coming by public transport to the hospital, for example parent P06 indicated that the train was “*quite expensive*” and parent P18 described the costs involved when having to travel by taxi.

*“It costs a lot of money to go there and then a lot of money to come back, plus if I go there [child] wants something from me like a balloon or something, and because I’m a single parent it’s quite hard. And if I have about two or three appointments in one week it’s too much.”* (P18)

This quotation highlights the particular difficulties of parents with lower household incomes, and families who have to attend multiple appointments. Furthermore, it illustrates a point raised by a number of other interviewees, that there may be additional costs in coming to appointments as parents persuade or reward good behaviour in attending children by purchasing ‘treats’, as in the following example.

*“Sometimes [child]’s like, ‘Oh have we got to go again?’ I’m like, ‘Come on [child].’ I bribe her, ‘Come on we’ll just go to WH Smith after and buy a book.’”* (P06)

In contrast to travel by public transport, comments regarding the costs involved in travelling by private means were more frequent and extreme, all of which related to payments for car parking near the hospital. Participants described parking costs as “*expensive*” (P03), “*horrendous*” (P05), “*ridiculous*” (P13) and “*extortionate*” (P13). The latter participant expressed the most intense views on this subject and discussed the unfairness of these costs for families with sick children.

*“Why do we have to pay? I don’t understand. I mean if we didn’t have the money, how would we afford eight pound car parking fees? It’s just disgusting. I don’t ask to be having to go there. You don’t ask for poorly children do you? And it’s not their fault and yet you still have to pay.”* (P13)

Difficulties with affording travel costs may decrease parents’ ability or desire to attend. One interviewee noted this and suggested a potential solution.

*“Maybe sending more information when they send out patients’ appointments, explaining to people where the cheap parking is. Because I know a few people that have actually had to go and they’ve spent like ten pounds or more just for parking. And obviously that will turn a lot of people off and they would not want to come for another appointment obviously.”* (P03)

However, another participant emphasised that although travel costs were troubling, the management of the child’s illness was more important and so difficulties simply had to be overcome.

**Interviewer:** “*So do you manage the costs and things?*”

**Parent:** *"Yeah I have to. She comes first, with her illness. If she's got to be seen, she's got to be seen."* (P20)

### The clinic environment

Reflecting on their experiences at General Paediatric outpatient clinics at the main hospital site, participants identified several aspects of the clinic environment that influenced the stress or difficulty of attending appointments. These included the surroundings and atmosphere of the waiting area, and the perceived threat of infection from attending children and other health risks.

### Surroundings and atmosphere

When asked about the space and surroundings in the BCH outpatient department some parents gave fairly positive opinions, such as stating it had a 'nice atmosphere' (P18), was not 'cramped' or 'claustrophobic' (P05) and was *"quite a friendly sort of environment, it's nice and light"* (P03). The child-friendliness of the main outpatient area was pointed out by two participants.

*"It's quite good, I mean as soon as you get there you do realise you're in a children's hospital, the colours, the toys, and the staff are normally quite good and friendly."* (P21)

*"There's no, 'You must sit in the red chairs' or, 'Do not move', as that tends to obviously cause problems as well because kids don't want to sit down, they want to wander round."* (P03)

Unfortunately the phlebotomy waiting area and clinic rooms, which many families attending General Paediatric appointments would need to visit, were identified as *"not very child friendly"* (P03) by one interviewee. This was deemed to be stressful for both the child and parent.

*"It's very clinical. So for a child to have gone from playing... to be sat in a corridor where there's nothing there... it's just a row of chairs, and then they go into the room where there's also nothing. There's nothing child friendly about the room. And I think that obviously adds to stress levels and that obviously adds to the parents' stress."* (P03)

In addition to the effects of the material surroundings of the clinic, participants also commented on the perceived noise levels and sensation of crowdedness within the waiting area. Interviewee P10 felt that the noise was *"fine."*

*"It's just loads of screaming kids, it's just like playgroup... It's what you'd expect in a children's hospital waiting room."* (P10)

However, parent P09 was negative about the noisiness of the department and commented that this affected both her and her daughter's attitudes to waiting in the clinic.

*"It's a huge room with no soft furnishings, so it's just really loud and echoey, and of course full of children squealing... I don't like it, I have never liked lots of loud noise particularly echoey loud noise. [Child] doesn't like it either, she doesn't like lots of noise."* (P09)



Similarly, two parents remarked that the waiting area was “congested” (P11) and “chaotic” (P18), and that there was little available seating due to “overcrowding” (P11). Participant P13 went so far as to describe it as “like a cattle-shed” (P13).

Participants P15 and P21 also mentioned negative attitudes toward being in the outpatient department due to the emotional impact of seeing extremely ill children. Parent P15 described being more comfortable at an outreach clinic than the main hospital because “you know that there’s sick children there [at BCH]” and so it may feel more ‘scary’ and less relaxed for children. Participant P21 spoke about similar reservations due to her own feelings about hospitals.

*“While you're in hospital there's so many sick children and it just reminds you of how the world can be harsh and cruel... A lot of sick people and for me it's like, that's your last destination, the death place... I would rather not go to hospital full stop.” (P21)*

#### Threats to health and wellbeing

Given this perceived ‘overcrowdedness’, it is perhaps not surprising that some interviewees expressed concerns about hygiene and infection within the outpatient department. Although one parent remarked that the children’s hospital was “a lot cleaner, a lot tidier” (P05) than other hospitals she had visited, three other participants talked about risks to their children’s health while attending appointments at BCH. For example, one couple spoke about their dislike of taking children to the hospital where “there’s more germs and bugs.” (P13)

**Father:** “I wouldn't put her down on the floor in the hospital I'm really funny about stuff like that... Hygiene. I just wouldn't do it.”

**Mother:** “Too much about foot, hand and foot is it? Foot and mouth diseases, all round nurseries at the minute.”

**Father:** “Foot and mouth disease. Hand or foot or something. As soon as we come out, we all have to clean our hands. I hate it. I feel horrible in there. We shower, don't we? As soon we come out we shower and bath. I think it just feels dirty.” (P13)

Similarly, parent P04 was extremely concerned about potential “cross-infection” and wouldn’t let her children play with any of the toys or books in the waiting area “after a whole day of sick children” touching them. Furthermore, parent P09 pointed out the additional challenges involved in bringing children with severe allergies to the clinic, particularly when they are younger and less aware of the risks.

**Parent:** “There’s always food everywhere... You’d expect a hospital to be safe but actually it is probably more dangerous in the hospital than it is walking to the hospital because bits of food, and they only have to pick up a little bit and eat it.

**Interviewer:** *“And how does that make you feel when you know you’ve got an appointment coming up?”*

**Parent:** *“Quite anxious really... And me too, I mean I’ve had an allergic reaction at the Children’s Hospital... It can be quite stressful when you’ve got children there and there’s often a wait and they can’t touch anything.”* (P09)

#### ‘Knowing what to expect’ in the outpatient department

A topic that recurred throughout the interviews was the importance of parents feeling that they knew ‘what was happening’ or ‘what to expect’ when attending appointments. This was frequently mentioned as either a source of frustration or of feeling at ease. For example, while participant P08 described feeling “easy” prior to clinic visits because she knew “*what’s going to happen and what the routine basically is*” (P08), two other interviewees noted a general dislike of ‘not knowing.’

*“Everyone’s rushing around and you don’t know whether you’re coming or going.”* (P05)

*“I don’t like not knowing what to expect and how long you’re going to wait, and what the receptionists and the doctors in general are like.”* (P07)

Although these participants mentioned knowledge of the ‘routine’ and the manner of the staff, the aspect that concerned most parents was knowledge about their potential waiting time in the clinic. According to interviewees in this sample, waiting times were highly variable and a lack of information about delays in appointment times caused much frustration and some practical difficulties.

Participant P05 shared her irritation regarding this lack of communication.

*“You’re not guaranteed to get in at the right time you’re supposed to. You could be waiting forever, which is quite annoying... It’s not so bad when someone comes out and explains instead of just leaving you sitting there, that’s what annoys me. When you’re just left sitting there and you don’t know what’s going on.”* (P05)

The same participant noted that it wasn’t “*too bad*” (P05) on occasions when the receptionist informed families that they were running behind and patients would be seen as soon as possible. Both participants in interview P21 highlighted the variability of waiting times and the need for greater communication from hospital staff, especially as working parents.

**Father:** *“It’s not predictable, you can’t go down there and say that, ‘Oh, I’m going to be there for 45 minutes to one hour.’ It varies. You could be there and could be seen in the next 20 minutes, you could be there and you wouldn’t be seen for the next 2 hours...”*

**Mother:** *“If the doctor’s running late, if they had a notice to say these appointments are running late then at least you’d know you’re going to be there for a while.”*

**Father:** *“Then you can inform your employers. Feedback to them and say ‘Yes, I’m going to be here a bit longer.’ But you’re there and you’re at the mercy of the doctor until you are called, there’s nothing much that you can do.”* (P21)

Similarly, parent P13 pointed out that lack of information about waiting times in clinic had implications for childcare of other children, and having to rely on wider family members.

*"I have to get somebody in the family, luckily we've got that, to take [patient's sibling] to school or pick her up while we're at hospital, because you don't know how long we're going to be." (P13)*

Thus, uncertainty was associated with frustration and potential impacts on parents' work and other children in the family. There were also greater difficulties in managing children while waiting for consultations, which is highlighted in the following excerpt and will be described in more detail in the next section.

*"Obviously if you're waiting ten minutes and your child's getting upset, ten minutes can feel like an hour if no one knows what's happening. And that's when people start getting aggressive and they'll start berating the staff, and then there's more problems." (P03)*

The ticketed queuing system in the BCH outpatient department was thought to influence the uncertainty and frustration of waiting times, though participants presented opposing views on this. Interviewee P07 described frustration when it appeared that queue numbers were not adhered to, while participant P03 felt that the system "worked well."

*"If you see other people coming in after you and they go in before you to the same the doctor you're seeing, you're like, 'That's not right. Why have they gone in before? They had a ticket after me.' And that really, really frustrates us because there's not really a lot you can do about it... You're like, 'Hang on now, three people just come in after me. I've been here for the last hour, hang on that isn't fair.' So annoying." (P07)*

*"I think it's very clear as to who's next and everyone's got a ticket, and everyone knows where their place is really. I think that works really well, because everyone can watch the numbers and they know that someone's being seen, even if they don't know who's being seen they know that their number's getting closer. And even if it's an hour or so, people can see that there's progress." (P03)*

### Managing children

One of the most stressful aspects of attending appointments cited by participants was managing the behaviour of children before and during the visit to the clinic.

#### Bringing children to appointments

First, parents had to successfully bring children to the hospital despite sometimes encountering resistance. Some children were apparently 'used to' attending, particularly those who had been going to BCH since infancy, and therefore raised few objections to attending.

*"I think as they've just grown up with loads of medical appointments, I don't think they even consciously think about it. I think it's just something that happens, sort of like cleaning their teeth. Something they don't like but they have to." (P09)*

Parents of other children had to deal with some resistance, but managed this by 'putting their foot down' (P09).

*"Even if she didn't want to go, she'd go. If she had an appointment, she'd go. Even if I have to drag her there." (P19)*

Alternatively, as aforementioned, some interviewees made promises of treats for good behaviour. Some families went shopping in the city after their appointments, while two parents specifically mentioned 'bribing' their children.

*"I have to bribe her and say, 'Come on, if you go I'll get you a balloon when we're coming out', to calm her down. And so she looks forward to having the balloon afterwards." (P18)*

Older children and adolescents seemed to be particularly difficult for parents to manage. Objections to attending were sometimes perceived to be mood-dependent.

*"She doesn't like hospital. Well, one day she does, one day she doesn't. It depends what mood she's in. She's one of those teenagers, 'I don't want to do it today thanks mum.'" (P04)*

Further, one participant noted that her twelve year-old daughter didn't like to be treated as a child or to be surrounded by young children at the clinic, and so may be "getting to the point where she's not going to want to go to the Children's Hospital anymore" (P09). In one case the refusal of an adolescent child to attend the appointment resulted in non-attendance.

*"[Child] came in from school in a really foul mood and decided she weren't going to the hospital at all... She just didn't want to go at all... I phoned them up the following morning and let them know, and said, 'Would you be able to rearrange another one? My daughter was having one of her teenage tantrums.' So we just couldn't go and it would have been too much stress." (P07)*

#### Entertaining children in the waiting area

Many interviewees commented on the difficulties of 'keeping children occupied' (P11) while waiting in the clinic for appointments. Parents reported that children didn't like waiting (P15, P16, P18) and became "restless" (P10), "frustrated" (P18), and "bored" (P19). It was conveyed several times that long waiting times could be tolerated by adults, but that children neither could nor *should* have to wait for such long periods, particularly when they were young or especially unwell.

*"I suppose you can sort of tolerate it and be bit more patient, but it's more hard when you've got little young children... especially if they're not well." (P11)*

*"We're not particularly bothered about having to wait as adults, but for [child]'s uncomfortableness, discomfort, I don't see why children should have to wait really. The way that they are treated at the children's [hospital], it's a bit like a market isn't it? Unfortunately. You feel like a number, not like a person." (P13)*

This second quotation illustrates that not only was waiting with young unwell children stressful for parents, but it also impacted on their perceptions of the quality of care received and decreased their sense of 'feeling cared for' by the hospital.

Some participants made non-specific positive comments about the presence of a play area and toys within the outpatient department, stating that this was "good" (P02) or "fine" (P19). However, five interviewees explicitly noted that more activities were required.

*"Just need more toys for the little ones to play on." (P01)*

*"Not got much for the kids to do. Because they're sitting in there for an hour or two waiting to go in, there's nothing much for them to do. So you got to take stuff in yourself to keep them occupied." (P20)*

As noted by the latter interviewee, parents attempted to provide their own entertainment for children. However, parent P11 pointed out that "even though you're there as parents, with other games and activities", this was often insufficient during long waits.

*"Sometimes takes up to about three hours, two hours, and they get bored easily. Considering it's a children's hospital they need more facilities for the children... Or have a nursery nurse or a teaching assistant to play with, keep children occupied." (P11)*

Lack of 'things to do' was perceived to be a particular problem for younger and older children. That is, children who were aged roughly between five and ten years old seemed to be well catered for with play facilities, but activities were lacking for infants and near-adolescents.

*"It's just this one [four year-old child]. There's nothing for her to do there at all... I know [eight year-old] always plays on the caterpillar that you crawl through. She loves playing on that. And [four year-old] might play on that for five minutes and then she'll be bored." (P07)*

*"They do tend to forget when you go to hospitals that teenagers have to go. And they seem to do like stuff for the younger children." (P07)*

Many of the parents in this sample found waiting in the outpatient department with children difficult and taxing. However one interviewee stood out as experiencing more than average levels of stress and challenging behaviours by her children.

*"[Four year-old child] will start running round knocking on people's doors, and trying to open the doors, and you're like, 'Just keep still please.' It's very stressful..." (P07)*

*“The older one [8 year-old] does have ADHD so she can be really, really hyper... She hasn’t got a very big attention span so she’ll be running around screaming, going, ‘How long’s it going to be, how long’s it going to be?’ So by the time you sometimes get into the doctors you’re just so stressed, you’re just like, ‘Let’s just get this over and done with.’ It’s very, very stressful.” (P07)*

These quotations illustrate that some attending families face multiple interacting difficulties, such as managing several children and children with additional care needs with no additional support from spouses or wider family members. It also demonstrates the potential impact of these difficulties on children’s healthcare as parents enter the consultation with the doctor so stressed that their attitude is one of ‘getting it over with’, meaning a less engaged and informative discussion, less relationship building, and ultimately less positive input into managing the child’s condition.

#### Children’s behaviour during the consultation

Finally, a small number of participants discussed their experiences of managing child behaviour during consultations. Although infants and younger children were perhaps less expected to ‘behave well’ and easier to manage physically, older children were expected to comply with parents’ and doctors’ instructions, not to be disruptive and, in those approaching adolescence, to actively contribute to the conversation regarding their condition. Two parents of five and six year-old children were pleased to report that their sons were highly cooperative during appointments.

*“He knows what [consultant]’s going to ask him before she asks him. And he just literally, tummy out, t-shirt up, feel the tummy things like that.” (P08)*

*“It’s just a matter of going in, he does what he’s asked to do and then he’ll go.” (P10)*

This compliance was taken as a sign that the child was “fine” (P08) or “not bothered” (P10) by appointments, meaning less stress for these participants.

Parents dealing with disruptive children, on the other hand, would naturally find this demanding. This seemed to be a problem predominantly when parents had to bring more than one child to the clinic, and so interviewees described attempts to avoid this by arranging appointments when alternative childcare was available. For example, parent P09 expressed a preference for appointments during school hours for the following reasons.

*“The younger two are a bit hyperactive so it would be a complete nightmare... I would have them in the room interrupting and just generally misbehaving probably.” (P09)*

As mentioned above, older children and adolescents were increasingly expected to actively contribute to consultations. This was an ongoing goal for some families, as illustrated in the first

quotation below. Other participants found this to be an uncomfortable experience due to their child's behaviour, as exemplified in the latter quotation.

*"I've been trying to encourage her to do the interacting [with consultants], but she doesn't like to talk to them all that much... She's taking quite a lot of encouragement. I think because she's shy. Even at the beginning when [consultant] says, 'How are you and what have you been doing?', she doesn't like to say anything." (P09)*

*"She was so rude to [consultant] sometimes... He's being really polite, asking her 'How's school? Is there anything you'd like me to do?' She's just like grunting. '[Child] talk nicely. He's asking you questions.' And then I'm just sitting there thinking, 'I wish I wasn't in this room now, I wish the ground would swallow me up.' Because it can be really embarrassing." (P07)*

### Theme summary

The findings presented in this theme illustrate many issues that contributed to the stressfulness of attending for parents, including the cost and complexity of travelling to the appointment; the atmosphere and perceived health risks of the clinic environment; knowing what to expect while waiting for appointments; and managing children's attitudes and behaviours before and during consultations. These perceived stressors affected interviewees' perceptions of their own abilities to manage or to cope with attending appointments. This meant that the more anticipated difficulties, the lower parents' confidence, desire or motivation to attend. Conversely, when attending was perceived to be 'easy' due to few or minor difficulties, interviewees were confident in their ability to attend.

#### **5.3.2.3 Theme three: Evaluations of healthcare**

The third theme presents findings related to participants' perceptions and experiences of the healthcare provided for their children, and focuses on the dimensions of care that were valued by parents. This encompasses evaluations of 'quantitative' and 'qualitative' aspects of relationships with General Paediatric consultants, and perceptions of care delivered by a specialist children's hospital in comparison with GPs or general hospitals.

#### Relationships with General Paediatric consultants

Relationships with General Paediatricians appeared to be extremely important to several participants, particularly those whose children had long-term health conditions. This parent-doctor relationship was perceived to be vital for facilitating management of the child's condition through improved communication and collaboration.

*"It's important to me to keep up a relationship with the consultants. For my peace of mind so if something does happen in the future, I've got that relationship already built up and I can discuss it with them... It's actually a relationship of communication between you and your consultant." (P12)*

**Interviewer:** *"And the relationship with the hospital doctors [is important] as well?"*

**Parent:** *"That's a hundred percent, two hundred percent [important]. Because together we can manage it [the health condition], and together hopefully we can cure it and she can have a normal life... It's working together to try and solve the problem or make it manageable." (P21)*

The quotation by parent P21 highlights the perceived importance of 'working together' to manage children's health issues, through combining parental experiential knowledge with consultants' professional medical knowledge. The development of such collaborative relationships with consultants was influenced by several factors, including the amount of time with the doctor and the quality of interactions.

#### 'Quantitative' aspects of relationships

Interviewees varied in the number of appointments already attended with the General Paediatric service and the period of time over which they had occurred. Two participants (P17, P22) had been to only one appointment at the time of their interviews, while others had attended many clinics over several years (e.g. P12 and P18). Parents who had seen the service more than just a few times were the ones whose children had serious or long-term conditions that required ongoing monitoring, including Kleefstra syndrome, epilepsy, obesity and recurring infections. For these families, there were also variations in the frequency of children's appointments, with three, six and twelve month intervals all reported. In many cases the regularity of appointments was dependent on the current severity of symptoms, so that families sometimes saw the consultant every one or two months, and sometimes just once a year. For example, parent P19 stated that as a result of more frequent kidney infections, his daughter's outpatient appointments had increased from *"a yearly visit"* to a *"three-monthly cycle"* (P19).

Parents were therefore generally satisfied with the frequency of their children's hospital visits given that appointment regularity tended to match condition severity and level of control. However, one interviewee did note that her child's condition was poorly controlled and felt that both General Paediatric and dietetic appointments were too infrequent.

*"Personally, I don't think they see her enough. 'Cause she only sees the doctor once a year... And we'd see the dietician a couple of months a year. And I could probably do with more advice on the dietician part... It's trying to get her to eat the foods." (P07)*



Satisfaction with appointment regularity was partly dependent on parents' trust in the consultant's judgement about how often the child needed to be seen.

*"[Consultant] said to me, 'If you'd like me to see you every three months, I don't mind.' I said, 'Well if you're happy seeing us every six months that's fine with me.' So we've stuck to the six month one now." (P18)*

However, the predominant reason participants gave to explain the acceptability of appointment intervals, was the ability to contact the consultant between appointments for advice or to bring forward the appointment.

*"I don't mind waiting the six months because I always keep a log anyway, if there's any more problems I'll ring them and say, 'Can she be seen a bit earlier? Because her problems have got worse.'" (P20)*

*"It was initially every 3 months, and then went to 6 months. But I'm just about to call [consultant] again... I'm a bit concerned because I think we need to increase the medication. But based upon what the doctor says, then we will act." (P21)*

Many participants whose children were expected to require long-term or ongoing care were given the phone number for their particular consultant so that they could call for advice when necessary between appointments. This was always viewed positively and some participants relied heavily on this resource for support and assistance with managing their children's conditions. For example, interviewee P13 reported calling the consultant to discuss increasing her daughter's laxative medication and interviewee P12 found it "useful" to be able to email her daughter's consultant.

*"It's a direct contact, but you're not having to phone. It's kind of like you can send a message and they'll get back to you in their time." (P12)*

Frequency of appointments and availability of the consultant outside of appointment times were thus associated with parents' ability to manage their children's conditions, and likely also contributed to the development of relationship with consultants.

Relationship development was also influenced by the *continuity* of the healthcare professional seen during hospital appointments. One interviewee expressed frustration when multiple healthcare professionals were encountered.

*"I hate when you go to the hospital and you see a different doctor every time, and then they're having to go through all your notes... You're being asked the same questions again, and it does get a bit annoying after a bit." (P05)*

Some families were transferred from the care of existing consultants to new consultants due to doctor 'busyness' or retirement. These parents mentioned no particular dissatisfaction with care

being moved to a new doctor, but did talk about the need to build new, equally positive relationships.

*“Took a bit of time, but she [new consultant] seems nice. She seems funny as [previous consultant]... It’s a shame that he’s left because he’s been a fantastic doctor to me and my family. There’s a lot he’s done, so I’m hoping this one can show as good as what he’s done.” (P20)*

Another dimension related to the ‘quantity’ of family-provider relationships was the actual amount of time spent with the healthcare professional during clinic visits. Participants who had experience of attending appointments at the Wychall outreach clinic reported that these visits were lengthy and unhurried, which was highly appreciated by parents particularly in comparison with their experiences at the main outpatient department.

*“We get all our answers done and all our questions answered and she’s in absolutely no rush. She doesn’t rush you. If you’re at the Children’s [Hospital] you can tell they’re on edge to get you out the door in a way. Although you get your answers, they’re still kind of trying to get the prescriptions written because they’re trying to say, ‘Hint, hint, you’ve gone over your 15 minute slot.’” (P13)*

This perception of appointments at BCH being rushed or curtailed was reiterated by two parents who had attended appointments only at the main hospital site. In both instances the child was ‘fine’ at the time of the follow-up appointment and so a lengthy consultation was perhaps unnecessary. However, both participants indicated frustration at the shortness of the visit in comparison to the prolonged waiting time in the clinic reception area.

*“The second time we waited an hour and a half for her and we was in there two seconds because she went, ‘Well is there anything you want to say?’ And I said, ‘Well not really because it [the urinary infection] is gone.’ So she went, ‘I’ll discharge you then.’” (P06)*

*“The last appointment we came to she was like, ‘How are you feeling?’ [Child] said, ‘I’m feeling fine’... ‘Blood tests are normal. Okay, see you in the next couple of months.’ And we were in with her probably about three or four minutes. We’d waited over an hour to get to see her.” (P04)*

The findings outlined above indicate several factors that contributed to developing relationships with consultants and parental satisfaction with care provided by the General Paediatric service. Specifically, participants valued appointment intervals that matched how well the condition was currently controlled; being able to access consultant advice outside of scheduled appointment times; continuity of the same doctor over appointments; and consultations that were temporally worthwhile and unrushed.

### 'Qualitative' aspects of relationships with General Paediatricians

Interviewees' evaluations of care were further shaped by perceptions of the 'qualitative' aspects of relationships with consultants, meaning 'how' care was delivered by individual doctors rather than merely 'how much'. Participants mentioned three relevant dimensions of healthcare professionals' characteristics and behaviours, including the doctors' perceived knowledge and competence, their demeanour towards both children and parents, and actions that made parents feel 'cared for.'

First, there were a number of instances where interviewees expressed positivity in relation to the consultants' medical experience and competence. For example, when asked to consider healthcare provided in outreach community settings, participant P04 emphasised that location was unimportant compared to the doctor's expertise.

*"You're still going to get the same care from that person, that qualification that they've got... As long as you have a private room where you have that qualified person looking after your child." (P04)*

Interviewee P13 similarly described the value associated with an experienced, knowledgeable and effective consultant, describing her daughter's General Paediatrician as *"a consultant who knows her stuff"* (P13).

*"It was almost like we were seeing the top dog again, and this person had just come in and said, 'Right we're starting from scratch, I've got several things up my sleeve, let's try doing this again', and reintroduce this pain drug, and it just seems to have worked." (P13)*

The second feature of family-provider relationships deemed important by participants was the interpersonal behaviour or manner of the clinicians when interacting with children and parents. Interviewees variously described General Paediatric consultants as *"lovely"* (P09), *"very pleasant"* (P22), *"really nice"* (P20) and as making them *"feel quite comfortable... so we can talk about our problems and diseases with them easily"* (P17). These positive traits had important impacts on children's care as they facilitated discussion between parents and professionals, and encouraged continuation with the healthcare relationship. One participant noted that her experience with a non-BCH paediatric consultant at a child development centre had been so negative that she withdrew her child from his care.

*"There was no kind of people skills there. To the point that I stopped going to the appointments, I wouldn't go. Because I'd come out crying. Just cancelled them. Said I didn't need them." (P12)*

Doctors who thoroughly explained illnesses, treatments and healthcare decisions to parents were especially valued, as in the following example where a mother talks about her feelings when her child was first diagnosed with epilepsy.

*“I was scared at first, but my mind’s been put at ease. Because [consultant] has explained it fully, and which I could understand.” (P15)*

Participants also frequently discussed how ‘child-friendly’ the hospital staff appeared to be. This included not only General Paediatric doctors, but also nurses, phlebotomists and reception staff encountered during the course of General Paediatric care. One interviewee described the nurses as *“not rude, they all treat you with respect”* as well as making *“the children not to be scared”* (P18), while another gave an account of a General Paediatric consultant putting her son at ease while in hospital for surgery.

*“When my son was going into theatre he [consultant] used to always make a coin come from behind the back of his ear and make him laugh before he went down. [Consultant] would be there to cheer him up. So he was a really nice doctor.” (P20)*

In contrast, two parents made negative observations about the child-friendliness of BCH phlebotomy staff, stating that they were *“not very friendly, they always look as though they don’t like children”* (P03) and had been *“abrupt, quite horrible”* on previous visits (P08). These participants emphasised the consequences of the healthcare professionals’ demeanour for their children’s behaviour in clinic, and subsequent health outcomes. Parent P08 noted that friendly faces *“make the child feel at ease, a lot”* and that the phlebotomist’s abrupt manner had made her son cry and have *“a fear of needles ever since”* (P08). Participant P20 further explained the link between the conduct of hospital staff, child behaviour and effects on delivering care.

*“When you’ve got children, to see a friendly face and a smile on their face, it manages them more easier to be relaxed. That’s what I think if the place is all friendly, children are going to be more happy and relaxed to work with... If the staff’s happy the children are going to be happy.” (P20)*

These perceptions of clinician’s demeanour and competence, and therefore quality of care, were in some cases influenced by participants’ own healthcare experiences.

*“The allergy clinic that I go to, I find the children’s one is much better. It’s much more friendly and they’ve got the time to explain things. And I’m not convinced on the competence of the doctor I see either, so yes I think she’s better off staying there [at BCH] as long as she can.” (P09)*

The third feature of relationships with General Paediatric consultants important for interviewees’ satisfaction with care was encapsulated in a statement by participant P22 who said that she no longer felt *“cared for”* by the service. For this parent, the fact that the doctor did not have all the necessary information readily available during the appointment and had not checked her son’s test results prior to seeing them indicated a lack of sufficient interest and disengagement on the part of the service. This perception may have been intensified because the family had no prior relationship

with this clinician, and so the interviewee referred to the appointment as merely “*an administrative exercise*” (P22).

This feeling ‘cared for’, incorporating notions of empathy, attention, and support from healthcare staff, was apparent in a number of interviews and seemed to play a role in parental coping as well as parents’ healthcare decisions. Positive examples of this concept included the clinician demonstrating concern for the impact of the condition and the appointment on the child; providing the parent with practical and emotional support; and demonstrating real interest in the family’s wellbeing by making time for them. This latter point was discussed in reference to other BCH services, but could as easily have been applied to General Paediatric consultants, and demonstrates the value placed by parents on healthcare professionals ‘going out of their way’ for families. The following quotations illustrate each of the above points relating to ‘feeling cared for’ in turn.

Empathy: “[Consultant]’s a lot happier seeing us there [at the outreach clinic], she says herself... She always says she doesn’t like to think that we’ve got to drag [child] to the hospital really, if she’s round the corner it makes sense for us to go there.” (P13)

Practical and emotional support: “Well [consultant]’s brilliant because we’ve been with her since the beginning and she’s done all the tests, and sent us here and sent us there, and she’s basically done everything for us. And I thank her a lot because without her we wouldn’t have found out anything and she’s one in a million really. I told her that the other day. She’s one of the doctors that always gives you a positive thought. She can tell if you’re down, she always picks you up.” (P18)

Making time for families: “[Child]’s consultant, [respiratory consultant] is very good. They do day shifts in that outpatient clinic... but whenever [child]’s been admitted or we’ve had to go through to A&E, [consultant] will always come and see him... I can’t fault him there because I know he’s busy with clinic and he’s still come and seen [child] and said give him this, this and that. And he’s started to get better then.” (P10)

Thus, by demonstrating empathy and genuine caring for children and parents, consultants strengthened their relationships with families, increased parents’ perceptions of quality healthcare, and improved parents’ coping and ability to manage their children’s conditions.

#### Outcomes of relationships with General Paediatric consultants

Through ‘quantitative’ aspects such as time and availability, and ‘qualitative’ aspects such as empathy, consultants facilitated the development of strong positive relationships with parents. This rapport was highly valued by interviewees and was associated with increased “*trust*” (P20).

*“You do appreciate seeing your own doctor, because you know you can’t go wrong with what he says.” (P10)*

This trust was not only valued by parents, but also led to significant changes in healthcare decision-making. For example, parent P18 had been referred to the children's hospital paediatric psychology service for help with managing her daughter's maladaptive and aggressive food-related behaviours. She did not perceive any value in attending this service even after an initial appointment and would have refused further visits, but was convinced to accept a second appointment solely due to her trust in the General Paediatric consultant's recommendation.

*"I didn't see any benefit of going there really, but she said to me it's good for her to go, they know what they're doing, they're doing their job. And with her being aggressive with the food and all that stuff, they know how to talk to her and stop her being like that. But I didn't see it from that point of view... So she said, 'What I'll do, I'll get you back with them', and I said, 'Oh, okay then. If you think it's good then we'll go.'" (P18)*

In combination with earlier-described effects on parents' managing their children's conditions (e.g. through medication control) and emotional coping (e.g. through making parents feel 'cared for'), this apparent influence on service use demonstrates the ways in which relationships with healthcare professionals can ultimately affect child health through parental management.

#### Beliefs about specialist paediatric healthcare

The second section under this theme focuses on participants' preferences for healthcare delivered specifically by General Paediatric consultants at a specialist children's hospital rather than GPs or paediatric consultants in general hospitals, and the key reasons behind these views. Many participants espoused a desire for their child to be seen by a 'specialist' in children's medicine.

*"[The] GP referred him for his diarrhoea problem. He said he can see the specialist then. We were happy about it, we thought it's going to be much better for him." (P16)*

One reason for the preference over GP care was a perception that doctors in hospitals had access to greater resources than those in primary care, including investigations and medicines. One parent remarked that *"GP surgeries haven't got x-ray machines"* (P04), while another observed that BCH consultants were able to prescribe medications that GPs either could not or would not.

*"The consultant prescribed an asthma medication which [the] GP wouldn't prescribe so that was a bit of an issue for a while... The problem is that medicines aren't licensed for children so I think the GPs often are a bit worried about doing it." (P09)*

A third parent emphasised that health problems could be dealt with by consultants more rapidly as they had more immediate access to test results and onward referrals.

*“If there’s a problem you can see a consultant and they can be referred quickly, and also you can chase up things at the hospital which you can’t necessarily in the community, because if you go to your GP and they haven’t got the results then they still have to chase it up. Whereas at least if you’re there then they can chase it up directly.” (P13)*

However, the main reason for this wish to receive BCH care as opposed to any other form of healthcare was the belief that consultants at the children’s hospital had the most experience working with children. This level of expertise was desirable for several reasons, including increased knowledge about paediatric medical conditions, enhanced ability to recognise symptoms and identify appropriate management strategies, and for parental reassurance.

Knowledge: [To the child’s GP] *“Well you’re not paediatricians, you don’t know nothing about these children’s individual problems. So you might know about like childhood asthma and that sort of thing, but you don’t know about these little things.” (P07)*

Recognising symptoms: *“The children’s hospital doctors, they do have more experience with children as compared with the other doctors... I think because they have seen so many kids who are born with the allergies, they notice what’s the difference and how they cope with the allergies, they know better how to treat those kids.” (P17)*

Reassurance: *“I would’ve still preferred my child to go to the Children’s. I think it’s just like reassurance and you feel secure... Even though probably at [general hospital], the doctors which I’m going to probably see, they’re going to be specialised paediatricians and they can probably have the same qualification and the same experience. But I don’t know, for some reason you think the Children’s [Hospital] are more aware of the child’s problem, understanding, and they’re more child friendly probably.” (P11)*

Despite acknowledging that consultants at general hospitals may have the same qualifications and amount of experience, this participant still felt that consultants at BCH would have more ‘expertise’ in caring for children. One parent further asserted that because of their greater experience with children BCH consultants better understood parental concerns, and so demonstrated more empathy compared to community paediatric consultants at a child development centre

*“She was under [consultant] in the community before and I wasn’t happy with the support I got from them. But it’s been consistent from the Children’s. And I think the Children’s know their stuff. So whenever you need to question anything you know they’ve got the answers there and they’re happy, and they understand the anxieties that a parent may have. Whereas in the community I suppose there’s not that much empathy... [At BCH] they all treated you as an individual, they take on board what you say.” (P12)*

In addition to the perceived benefits of being seen by a children’s hospital consultant, participants’ preference for ‘specialist’ care was also associated with a belief that GP care was for ‘general’ issues only. Two interviewees commented that doctors in primary care could not deal with “*little things*” (P07) or “*small issues*” (P04) meaning conditions that were uncommon or highly individual. For instance, participant P04 described GPs as treating “*colds, coughs, sore throats, ear infections*” as opposed to “*lumps, bumps*”, and parent P07 commented that GPs were perhaps able to deal with

common childhood illnesses such as asthma, but did not have the necessary knowledge to treat her daughter's coeliac disease (see quotation on preceding page). In some cases GPs themselves perpetuated this belief by immediately or frequently turning to secondary care colleagues for advice rather than treating children's conditions personally.

*"He said that he didn't want to really try anything because obviously he wasn't that much of a specialist in children, so he just sent him to the Children's Hospital." (P08)*

Accordingly, there was a parallel view that paediatric consultant care was for uncommon or serious conditions. That is, specialist care for 'special' cases (and general care for 'general' cases). For instance, interviewee P13 declared that *"consultants don't give you an appointment to be seen for your child for nothing"* (P13), suggesting that a certain degree of severity was believed to be required to warrant a secondary care appointment. This point was borne out by participant P04 who noted that now that her child was *"fine"* (i.e. no longer 'serious') she could potentially be reviewed by a GP rather than *"troubling a consultant with it"* (P04). Given that many participants in this sample perceived their children's illnesses to be unusually serious or rare, it is not surprising that consultant-led healthcare was often thought to be most appropriate.

Finally, there was evidence to suggest that participants' preferences for BCH paediatric care were influenced by past experiences. Both positive encounters with the children's hospital and negative experiences with other services led to a desire to be seen by BCH consultants. For example, when talking about the children's hospital parent P06 reported that her *"whole overall experience has been excellent."* As a result, when questioned about the possibility of receiving care from a general hospital, she stated that she would *"personally prefer this one [BCH] because it is a good hospital and it's one of the best"* (P06). In comparison, parent P22 described what she felt to be an extremely poor experience of care delivered by a general hospital as they failed to accurately diagnose her son's health problems. In the following quotation where she gives an account of her conversation with a consultant at the general hospital, she vows always to attend BCH in future.

*"There's no way I would bring [child] back to [general hospital]... In future I would always go to the Children's Hospital because you neglected him. You sent us home with just a piece of paper that was a printout from the computer about chronic fatigue... And you completely misdiagnosed it... I shall speak to [consultant] at the Children's Hospital who's prepared to look at my son, unlike you." (P22)*

### Theme summary

The findings above demonstrate that quantitative, qualitative and collaborative aspects of interactions with General Paediatric consultants influenced parental satisfaction with healthcare, the development of parent-doctor relationships, and improved coping and control of health issues.



Additionally, parents valued BCH General Paediatric care as higher quality, 'exceptional' care for their children. This valuing of the care delivered by individual doctors, the specialist care delivered by BCH, and the additional increases in control of symptoms conferred by these provisions, led to increased motivation to attend appointments. Additionally, as a result of strengthened interpersonal relationships with consultants parents were disinclined to miss appointments in case of 'letting down' the doctor.

#### **5.3.2.4 Theme four: Perceived seriousness of the child's condition**

When talking about their children's health issues, parents conveyed views about how 'serious' or not serious they felt the conditions were. This notion of seriousness incorporated perceptions of health conditions as non-trivial, significant and worthy of concern, requiring earnest attention and concerted responses from parents. Views were expressed both directly in comments about seriousness or severity (of the condition, symptoms or consequences of the illness), and indirectly in discussions of troubling aspects of the child's condition and parental worry. For example, expressions of parental concern included parents feeling "upset" (P01), "worried" (P14), "sorry" for the child (P06), "sad" (P13), and "scared" (P15). Several interviewees reported how difficult it was to see their child enduring episodes of pain or intense symptoms, describing this as "hard" (P01), "horrible" (P05), and "awful" (P08). Conversely, perceptions of decreasing condition severity were associated with feeling "happy" (P03, P08), relieved (P04) or in one case "proud" (P16).

Several children had been clinically diagnosed with the 'severe' form of a condition, such as asthma or PKU, which naturally led parents to see the issue as somewhat serious. Other children's conditions were variously described as "mild" (P15), "minor" (P04), "very serious" (P10) and "really severe" (P13). However, parents' beliefs about the severity of their child's illness were not a simple reflection of the type of condition that had been diagnosed. For example two parents who had daughters diagnosed with epilepsy differentially described the illness as "not that serious" (P20), and "very serious" and "could be life-threatening" (P21). Rather, the perception of seriousness was determined by a variety of additional factors and sources of information, including the perceived impact of the condition on the child's physical, social and emotional wellbeing, the frequency and severity of symptoms, comparisons with other children and conditions, and information from healthcare providers.

#### **Impact on the child's physical functioning and wellbeing**

One factor that influenced participants' beliefs about the seriousness of a health issue was the perceived impact of the condition on the child's bodily functioning and physical wellbeing.

Interviewees mentioned worrying effects on aspects of general wellbeing, such as sleep disturbance, tiredness, weight loss, or inability to gain weight in younger children. However, much of the talk around 'serious' impacts on children's wellbeing centred on consequences of the health issue for performing basic functions, including eating, standing, walking and toileting. Issues with urination and defecation were of particular concern, and came in several forms. Some parents reported their child not being able to 'go' which was often painful, or having pain when 'going' as in the following case where the child had a urinary infection.

*"She was going, 'It hurts, it hurts, it hurts'... So yeah, it was serious, because when she had a wee it was hurting her and you can't live life like that, can you?" (P06)*

Other children had difficulty preventing themselves from toileting and had 'accidents' at school, and still others required help or supervision to use the toilet due to risk of seizure or physical incapacity to walk.

*"By the second week you could tell it was something more serious... He was so dizzy he couldn't stand up, and he had to support himself. Going to the toilet we had to escort him because I was scared of him falling over." (P22)*

Naturally, the expectation to be able to perform these and other basic daily functions increases with children's age, such that issues with toileting became more worrying for parents as their child got older, and much concern was expressed about these problems in the oldest children. For example, one parent had a 14 year-old daughter with coeliac disease who had ongoing problems controlling her bladder and bowels which had persisted since early childhood. She described the concerns she had years earlier as the child had progressed towards adolescence.

*"She was coming up to nine, ten, and I'm thinking right she's going to be starting high school now. Definitely can't have this at high school." (P07)*

Such problems with excretion and self-care not only indicated to participants serious problems of physical functioning, but also resulted in significant practical consequences for parents and likely emotional and social consequences for children, including distress and embarrassment when problems arose while the child was at school.

*"She'd come home out of school crying, she'd had an accident and they made her stay in the same pants. And it really did upset her to the point where she didn't want to go back." (P19)*

At an even more fundamental level of functioning, problems with children's breathing or heart rate were also taken as markers of concern. Given the necessity of these processes for living, such concerns are entirely logical and were noted by several participants, including one parent whose teenage son was admitted to hospital with a racing heartbeat.

*“They done various tests on his heart, they did lung function tests, they scanned his heart. Now that week was the longest week in my entire life... You can’t help but then think, ‘Oh my god, there’s something wrong with my son’s heart.’” (P22)*

A second mother whose son had a severe asthma attack requiring emergency care to help his breathing and to slow his heart rate described this as “*very, very, very serious*” and that it “*frightened the life out of*” her (P10). In further support of this point, one parent explicitly commented that their child’s allergic condition was *not* very serious because it did not affect their ability to breathe.

*“He gets red rashes over there, but he’s not out of breath or things like this so... not that severe.” (P17).*

Linked to these views on the effects of health conditions on functions essential for life, some interviewees expressed their perceptions of seriousness by alluding to risk of mortality. Several parents stated that their child’s condition was not life-threatening and therefore “*not that serious*” (P20). A mother of a young child with a rare chromosomal disorder noted that her daughter’s accompanying epilepsy “*could affect her in that capacity*” (i.e. result in death), but she denied that the syndrome itself was serious.

*“Well it’s not life-limiting. So to me that’s serious.” (P12).*

Conversely, several interviewees perceived their child’s health issues as serious specifically because of the risk of mortality. In one instance this was seen as a long-term risk.

*“With coeliac disease I’ve explained some of the problems to [child]... If you don’t stick to this diet rigorously, the things that can happen. It can lead to, say, cancer and it can ultimately lead to death, because it can shut all your organs down.” (P07).*

In another case, a mother believed that her child’s epilepsy “*could be life-threatening*” (P21) and was especially worried about serious accidents occurring during seizures. In the week preceding the interview the child had had a fit and fallen while going up the stairs, so her mother’s worries were clearly had some grounding.

*“She tends to try and stand there [in front of the fireplace]... I was like, ‘[Child] you’ve got to move from there’ because if she had a fit she would just drop back on the fire, so I think it’s pretty serious.” (P21)*

### Impact on the child’s social and emotional wellbeing

In addition to the impact of health conditions on children’s general physical wellbeing and basic functioning, participants also worried to a lesser degree about the influence of health problems on their children’s emotional and social wellbeing. For instance, one parent was concerned about their child being bullied as a result of their overweight problem. Others described the emotional distress felt by children in response to their symptoms. This distress was most often described in relation to

children who experienced pain, which in turn contributed to the perceived seriousness of the condition.

*"It's just because she's in pain, it's not her fault, she's just screaming in agony. You can see it in her face and her tears, she just wants to be cuddled because it hurts."* (P13, Father)

Parents also mentioned concerns about the effects of ill health on their child's education, either due to occurrence of illness episodes during school time or needing time away from school because of prohibitive symptoms or treatment.

*"He was in quite a lot of discomfort at school and all they did really was just lie him on a sofa and he just did that all the time he was at school... He did have to have about two weeks off school because he was on a clear out."* (P08)

Moreover, seriousness was further increased when parents believed there was a potential bearing of the health condition on the child's *future* social wellbeing, for example on their ability to live independently.

*"We're thinking about when she's older. She would want to do normal things like drive and maybe even live on her own, but how do you live on your own if you've got epilepsy?"* (P21)

#### Frequency and severity of symptoms

Interviewees' reports suggested that the level of impact on the child, and therefore the perceived seriousness of the condition, was in turn influenced by the combined frequency and intensity of detrimental symptoms. Thus, conditions in which symptoms or illness episodes occurred highly frequently or even constantly were seen as very serious, but only if the symptoms were also severe or had significant impact on the child's wellbeing. If symptoms were frequently present, but had only a little impact on the child's physical or social functioning, the condition was less likely to be seen as very serious.

To illustrate, three participants had children with conditions that involved highly recurring or continual symptoms which significantly impinged on their general wellbeing or bodily functioning. One parent's infant son had been "*constantly ill*" (P11) with viral infections that had affected his eating and therefore also his body weight; another parent's child had chronic severe asthma involving daily control of respiratory symptoms and regular critical breathing problems (P10); and the child of the third participant had problems with eating, toileting and "*excruciating*" (P13) pain that had rarely let up in the eleven months since the child was born.

**Mother:** *"She has pain every time she swallows and severe constipation."*

**Father:** *"She wouldn't gain weight... She can't go to the toilet without having pain."*

**Mother:** *“It just seems to have been going on since she came in the world really.”* (P13)

Due to the continual and intense pain and problems associated with their infant daughter’s condition, these latter parents stated that the child’s health issue was *“terrible”* and *“really severe”* (P13). The other parents similarly perceived their children’s conditions to be very serious and reported especially high anxiety about the illnesses. In contrast, participants P07, P16, P18 and P20 had children with health conditions involving continual or very frequent symptoms (bowel control issues, diarrhoea and tired limbs, obesity and heavy breathing, and epileptic ‘spacing out’ respectively). However these conditions impacted less on the children’s vital bodily functions or levels of distress or wellbeing, and consequently were not perceived to be as exceptionally serious or intensely concerning.

Likewise, conditions in which symptoms were severe were always seen as serious, but were less concerning when episodes occurred occasionally rather than continually. For instance, two interviewees had children who experienced epileptic seizures. While one child had recently been having *“three or four fits a day”* (P21) the other had only had *“three in the two years”* (P15) since the seizures had begun. As a result, the first parent described her daughter’s condition as *“very serious”* (P21) while the second parent observed her child’s epilepsy *“might be a mild one”* (P15).

Unsurprisingly, health issues with low frequency and low intensity symptoms were less likely to be perceived as serious. This included conditions that had previously significantly impacted on children’s wellbeing, but were now improved and under control. Interviewee P04 described being extremely concerned about her daughter’s condition when she had ongoing *“really bad pain”* in her joints. However, now that the health issue was well managed, the parent observed that her child was *“not a quarter of the pain she used to be in”*, and given that she no longer needed treatment stated that *“on the scale of what children can come to hospital with, I think hers is very minor.”* (P04). In this way perceived seriousness of a child’s condition is likely to change over time as the incidence and intensity of symptoms are affected by disease progression, child development, and medical treatment, thereby altering the degree of impact on the child.

#### Comparing the child’s condition with others

The sections above present some of the reasons *why* parents perceived health issues as serious or not; that is, the factors that indicate seriousness. However, in order to evaluate seriousness parents also used external information to determine the degree to which they should be concerned. To make sense of and explain the severity of their child’s condition, participants compared the experience of their child to healthy ‘normal’ children, to other children with the same condition, and also

compared the condition to other health disorders. In several instances parents compared the condition of the child in question to the illnesses or experiences of their other children, or indeed to their own experience. Comparisons were often made in terms of the level of impact of a condition on functioning or general health, in agreement with the findings above.

First, parents gleaned indications of seriousness by considering whether the symptoms were 'normal' or not. One mother was convinced that her child's heavy breathing was problematic and asserted to the child's GP that *"it's not normal for a baby to breathe like that"* (P18). Similarly, participant P07 declared to her child's GP that there was *"something wrong"* with her daughter and it *"can't be right at five years old"* (P07) for her to still be soiling herself, drawing comparisons between the experience of her own child and usual behaviours for five year-old children.

Other parents contrasted their child's experience with those of children with the same or similar conditions. One participant acknowledged that, as above, comparison to a normal child would indicate her child's chromosomal disorder and disabilities to be *"pretty serious"* (P12). However, she also noted the following.

*"If you compare her to a child with different disabilities then it's not [serious]. I'd put her in the middle. She's probably one of the most independent at school, which she goes to a special school. So, on a spectrum she's on the lower half of things being serious."* (P12)

This demonstrates the parent's evaluation of the child's functioning in comparison to other children with similar health issues, and her conclusion that the condition is not as serious as in some cases. In the same manner, interviewee P19 compared his daughter's urinary infections to those experienced by his other daughter, the child's sister; P20 compared her child's symptoms of epilepsy to her own experience of the condition; and P02 compared her daughter's seizures to the child's own past history of febrile fits. In all cases, knowledge of the alternative experience was used as a benchmark against which the seriousness of the condition could be judged, as in these examples.

*"[Child's sister] had the same problem. But it has affected [child] a lot worse... She's getting it more often than [child's sister] had it, and it's lasted a lot longer."* (P19)

*"Her eyes used to roll up and the way she used to shake then was different. But the ones that she had this time, actually her whole body shook... I called the ambulance because it was something new to me."* (P02)

As well as judging their children's conditions by assessing them alongside others with the same or similar issues, interviewees also used comparisons with entirely different illnesses to evaluate and explain the seriousness of their children's health issues. In many instances this took the form, 'my child's condition is not as bad as having condition X.' For example, participant P06 expressed that although her daughter's PKU required intensive management and could have extremely deleterious

consequences, it would be *“a completely different story”* (P06) if her child had cancer or a brain tumour. Another parent conveyed that her child’s severe pain and problems with digestive processes were *“not on a par with her being disabled for the rest of her life”* (P13), citing spina bifida as an example of such a condition. This further demonstrates the link between perceived seriousness and impact on the child’s functioning, as disability by definition limits some aspect of bodily working. Participant P20 reasoned that epilepsy was *“not that serious”* and that *“it’s not going to do too much damage to her life”*, which was in stark contrast to her perceptions of her other child’s health condition. This interviewee’s son had a rare condition, Alports syndrome, which involved ongoing extensive treatment for incurable kidney failure. Given the risk of mortality of this more serious condition, and its pervasive impact on this child’s everyday functioning, it can be understood why this parent perceived epilepsy to be a far less severe health problem.

Finally, in one case a parent cited another disorder not to exemplify how her child’s condition ‘could be worse’, but to demonstrate her perception that both conditions were not too severe in terms of impact on daily living.

*“I wouldn’t say it was serious, I’d just class it as a lifestyle change like diet and that. It’s like having, I don’t know, diabetes or something. You just change your diet, low fat diet, whatever.”* (P07)

#### Information from healthcare providers

Participants additionally determined seriousness by considering the care and feedback provided by the General Paediatric service. Interviewees’ perceptions of seriousness were logically linked to explicit and implicit information conveyed by the healthcare professionals at the hospital. For instance, some clinicians made direct comments to parents about seriousness or concern, as in the following case.

*“Well they [the consultant] said it’s not as serious as some.”* (P15)

Parents also interpreted aspects of their children’s healthcare as indicators of seriousness, including the number and strength of medications prescribed and the frequency of scheduled appointments. The severity of one child’s asthma was reflected in a description of the increasing dosage of medicine required to control his symptoms.

*“The brown inhaler, which then went to the orange, which then went to the purple, then went to the dark purple and plus a tablet he has every night before bed.”* (P10)

Short intervals between appointments were thought to mean that the consultant perceived greater illness severity, while long waiting times indicated that the child’s condition was not believed by the consultant to be all that serious.

*“I was still anxious, I wanted to be a lot quicker, but obviously it was probably not a serious matter for them to see him that urgently.” (P11)*

Information regarding illness seriousness provided by GPs was not trusted quite as readily as that delivered by hospital consultants. Participant P04 commented that her belief that her daughter’s condition was “minor” (P04) and now under control was informed by the perception of the child’s GP.

*“When my GP turned around and said she really doesn’t need this [appointments for blood test monitoring] anymore, then we’ve just taken it to be, on the scale of what children can come to hospital with, I think hers is very minor.” (P04)*

However, three other parents reported occasions on which a GP had expressed minimal concern about a health issue, and this did *not* lead to reductions in parental concerns.

*“They’d say, ‘It’s just bedwetting, it’s normal in under fives.’ And then it would be, ‘Maybe it’s associated with bullying.’ And then when I went back for the third time they just went, ‘Okay we’ll refer you to the Children’s Hospital, but I don’t really think it’s anything. You’re worrying about nothing’... I was really annoyed and I didn’t know what to do. I didn’t know who to go to.” (P07)*

In these circumstances the GP’s views on seriousness were superseded by other sources of information or by enduring parental worries about factors such as impact of the condition on the child’s basic functioning. This demonstrates that participants’ perceptions about condition severity were informed by multiple strands of information, which differed in relative importance and which interacted to influence parental perceptions in combination.

### Theme summary

The findings presented in this theme show that interviewee’s perceptions of seriousness of health conditions were determined by the perceived impact of the illness on the physical and social wellbeing of the child, and further influenced through comparison of the child’s experience with others’ experiences and information from the General Paediatric service. Appointments were consequently thought to be important for obtaining information to establish severity and to learn about possible illness outcomes. Although parents readily observed the signs and symptoms of their children’s conditions, healthcare professionals were able to provide professional medical assessments, investigations, diagnoses, and estimations of severity in comparison with other patients. Clinicians were also able to track changes in the condition over time and to confirm whether symptoms had increased or decreased. As a result, interviewees remarked that appointments were important to attend so that children could be ‘checked’ and changes in conditions monitored. This checking of the child not only conveyed information about changes in the



seriousness of children's conditions, but also provided reassurance to parents who expressed much concern regarding serious health issues. Participants were thus motivated to attend in order to verify and monitor seriousness and to alleviate parental concerns. Appointments were also seen as important for reducing seriousness by facilitating control of the condition, and therefore decreasing the frequency, severity and impact of symptoms. This aspect will be addressed in the next theme.

#### **5.3.2.5 Theme five: Controlling the condition**

The fifth theme outlines participants' views and experiences of 'controlling' their children's health conditions. Participants talked about their efforts to control the condition in such ways as to minimise the frequency and severity of symptoms and the impact on the child, through both preventive and therapeutic measures. The resulting number and magnitude of symptoms, as well as the predictability of illness episodes, determined the extent to which health issues were perceived as well or poorly controlled. Thus, the concept of control was discussed both as an active effort exerted by parents and as a measurable quality of the health issue. Furthermore, interviewees described ways in which they felt 'in control' or felt a loss of control in trying to manage their children's health issues. These emotional aspects were expressed in terms of coping or powerlessness, and were closely interlinked with their perceptions of actual control of the condition.

The anticipated outcomes of bringing symptoms under control varied depending on participants' beliefs about the longevity of the health condition. Some parents perceived their child's illness to be finite and potentially short-lived, so symptom-reduction was necessary for the issue to become completely "*resolved*" (P08). Others hoped the condition would be overcome in the longer term, and sought control in order to facilitate the child 'growing out of' the condition (P21). A small number of participants perceived the condition to be enduring or life-long and therefore control was desirable for its own sake, to reduce the burden of ill health on the child. For some parents the potential for short or long term 'cure' of the condition was uncertain, yet control was sought nonetheless. Thus although motivations varied, achieving control of symptoms was desirable in all cases.

Within the sample there were parents whose children's conditions were already now resolved or well-controlled such that symptoms were no longer experienced or were maintained at a minimal level. Other children at the time of their parent's interview had problems that were slowly improving or being brought under control through the use of medications and other treatments. A third group had ongoing health issues that were poorly controlled, meaning that symptoms were experienced frequently and occurrence of illness episodes was unpredictable. Reported reasons for lack of control

included recent changes in medications, limited adherence to the prescribed treatment regimen, and changes in the condition due to the child's physical development.

*"She has severe asthma which was controlled until she hit puberty when it just went out of control again." (P09)*

In order to achieve control of their child's condition, participants undertook a variety of illness management activities, including ensuring the child adhered to a recommended diet by purchasing and preparing appropriate foods; remembering and administering scheduled medications; monitoring symptoms and giving alleviating medicines when necessary; preventing the child from coming into contact with known triggers of symptoms; managing pain by applying heat therapies; and care activities that would also be applicable to short-term sicknesses and general child care, such as giving fluids and ensuring adequate personal hygiene.

#### Factors that help or hinder control of the condition

Condition management behaviours and subsequent attainment of control of the health issue were helped and hindered by several factors. First, managing the condition was more difficult for parents when the care regimen was complex, requiring many significant changes to normal behaviours, or when activities were continual and intruded on daily life. For example, participant P04 reported having to make only *"simple changes"* to her daughter's diet by finding ways to include calcium-rich foods such as milkshakes, and had managed this successfully so that the child was *"eating a lot better now"* (P04). Similarly, participants P09, P10, and P17 merely had to omit specific food types from their child's diet, and P16 had to *"stop burgers and things, and chips, and junk food."* These changes were perceived as relatively straightforward and easily managed. However, interviewees P06 and P07 both had to provide an entirely altered diet as their children could not eat many 'normal' foods. Both parents reported having to order food 'on prescription', plan appropriate meals in advance, and manage their children's desires to eat other foods. The following excerpt demonstrates the huge effort involved in diet management in these circumstances.

*"It's hard work because everything has to be planned, I can't just go to the shop and buy a packet of biscuits, I have to order them on prescription. So I have to go to the chemist, order it, then they have to send it to the supplier, then the supplier has to send it back to them and they have to send it back to me... You can't just go and buy milk from the shop, you can't just go and buy bread, you have to make it." (P06)*

A second major influence on parents' ability to manage the condition was the behaviour of the child with regards to the required treatments and lifestyle changes. Some interviewees described children assisting with illness management by telling them when they were experiencing symptoms or requiring medicines, naturally avoiding allergy triggering foods, accepting medicines, and generally

knowing “*how to deal with it.*” (P04). However, the behaviour of some children made controlling the condition very difficult, usually by refusing to accept the prescribed medicines or dietary changes. Interviewees P07 and P18 both gave accounts of struggling to prevent their children from eating foods outside of their allowed diet.

*“It’s very hard because even though you have to be strict with them, she still goes behind my back and steals out the fridge and she has these temper tantrums, if you say no she’ll get a bit violent and she scares [her sister] then, so it’s really, really hard.”* (P18)

*“For the last few weeks she’s just been living on mashed potato with grated cheese, which obviously the dieticians said that’s not good for you, you’ve got to have varied. But diet’s gone really, really haywire. Breakfast she’s ok. It’s in the day if she goes out anywhere or if she has her own money, she just buys stuff, like munchies that she’s not allowed to have.”* (P07)

One parent also struggled to administer medicine to her child, highlighting the bad taste of medication as a barrier. This participant described the challenges she had delivering her child’s medication for PKU, which came in a gel and was prescribed as six packets over three time points per day.

*“For two years she wouldn’t have it, and they said to me she’s got to have it regardless, simple and plain as, it’s her medicine. And it’s like a wallpaper paste... There’s times when she’s made me cry and she’s gone ‘I ain’t having it’, and it’s took us two hours to feed her one packet of gel. When she was little I had to wrap a blanket round her and just shove it down her mouth because she had to have it. So that was hell. That was absolute hell.”* (P06)

Finally, daily management of children’s health conditions was affected by the support or lack of support parents felt they received from the child’s school. Participants reported frustration when the school failed or refused to help with managing the child’s condition. Interviewee P18 described a positive relationship with her child’s school in this regard.

*“The nurse keeps an eye on her there and the dinner ladies, because sometimes they let the children have seconds, but she’s on a vegetarian diet there because of her health problems so they keep an eye on her too.”* (P18)

In contrast, participant P07 discussed lack of support as the school refused to help enforce the child’s prescribed diet plan, and one father reported poor support from his daughter’s school in helping to manage the symptoms of recurring urinary infections.

*“We’d mentioned to the school about the water infections being a problem, because they weren’t letting her go to the toilet. We’ve always told her if she needs to go put your hand up and go. They weren’t letting her so she was having more and more accidents at school.”* (P19)

### Beliefs about controlling conditions through medication

Unsurprisingly, a key method reported for controlling children's conditions was the use of prescribed medicines. All parents in the sample whose children had been prescribed medication expressed confidence in the effectiveness of medicine for reducing symptoms or preventing adverse outcomes, though it was noted that sometimes drug types or dosages needed to be amended in order to be most effective. Some concerns were raised by parents about the negative long-term effects of using drugs to treat their children's conditions.

*"I don't want to keep on overloading him with antibiotics or any other medication at a young age because, like they say, if you give him too many antibiotics when they're very seriously ill, their body doesn't take well to it later on." (P11)*

However, in all instances where worries about medicines were conveyed, the perceived benefits for controlling the health issue were determined to outweigh the potential risks.

*"The best thing is to try and wean him down because them steroids are not good long term... [But] if it works to make him ok then that's fine... If it helps, it helps. I don't mind." (P10)*

Some children were given medicines when necessary to alleviate symptoms, including painkillers or 'reliever' asthma inhalers. Parents of these children had some control over the condition by reducing symptoms when they occurred. However, the majority of medicinal control, including the type, dosage and availability of medications, was controlled by healthcare professionals rather than parents. Some participants readily accepted this state of affairs, but others attempted to exert control regardless by questioning the clinicians' prescriptions. For some this resulted in conflict with their children's physicians.

*"I've had a few disagreements with the consultant... he said she doesn't need an EpiPen [an emergency auto-injector for allergic reactions] and I think she probably does so we've had a bit of a disagreement over that." (P09)*

For others, a positive relationship with the healthcare professional strengthened the parent's ability to control their child's condition through pharmaceutical means.

*"If I didn't have the relationship I'd got with the consultant at the minute, I wouldn't have felt comfortable ringing her today. No way would I've picked up the phone... [So] I wouldn't have upped her laxatives. Because I wouldn't have done that without asking. If I wasn't comfortable enough to ask, we would be probably catch twenty-two of this for a lot longer." (P13)*

## The importance of knowledge for controlling conditions

A major sub-theme that frequently arose in participants' talk about managing health issues was the importance of knowledge. This included different kinds of knowledge perceived as central to controlling conditions, and the various sources of knowledge used by parents.

### Knowing 'what it is'

First, when discussing their children's illnesses interviewees emphasised the significance of 'knowing what it is', both in terms of formal diagnosis and cause of the condition. Both of these aspects were felt to be important for parents exerting control over the condition. For example, one parent said "Once you know what it is, you can learn to manage" (P20). Another stated that, "If we know what we're dealing with, you can deal with what you know about" (P04), thereby suggesting that managing the condition would not be possible without knowing what it is, or having an accurate diagnosis. A third participant described the necessity of understanding why symptoms were occurring in order to then tackle them.

*"We haven't got to the bottom of what causes these viral infections. It's okay to have a cold and a flu now and again, but constantly every few weeks you just got this cold and viral infections. Why is it happening? So I want to know the cause of it. What can be done to prevent this?" (P11)*

Understanding the diagnosis and cause of the condition also enabled parents to feel more in control and to cope with the condition emotionally. For example, one mother described her satisfaction in finally receiving a diagnosis and another emphasised the emotional distress of not knowing 'what it was'.

*"Well nobody wants to know that their kid's not well, but after being 16 weeks to 16 months I was glad they diagnosed him. Because they'd just say bronchiolitis or viral wheeze, but they won't actually say asthma. I understand why, but it was nice to know that they recognised he had asthma." (P10)*

*"This is the bit that is still upsetting for me, because to this day I don't know what was wrong with him." (P22)*

The impact of diagnosis on feeling in control was also true for older children experiencing the health problems.

*"I think her [the child's] self esteem and confidence has grown since she's known about that's what it is. Because obviously she's not panicking about the unknown." (P04)*

### Knowing 'what to do'

The second type of knowledge that interviewees highlighted as important for controlling health conditions was 'knowing what to do' to manage symptoms. Many interviewees demonstrated knowledge of the actions they must take to keep conditions under control, such as administering medications and monitoring food intake. For example one participant whose infant son had experienced an allergic reaction to biscuits containing wheat reported learning how to prevent future reactions.

*"I didn't give him much, I just gave him two or three morsels, but after that in half an hour time he started throwing [up]... And for the next time I knew that I am not going to give him this." (P17)*

However, several parents reported having felt uncertain about how to prevent or manage their children's symptoms, which limited their ability to control the condition. For example, participant P14 described not knowing how to react to his daughter's fainting episodes when they first occurred, which had consequences for 'catching' or controlling the condition.

*"They said when she gets unconscious again, call the 999. And I think we [were] a little bit late because we didn't know, two or three times. I think the third time we called the ambulance... We already missed two places. They said if you come in first places that might be the easiest for us to catch the situation." (P14)*

Knowing what to do was linked to the aforementioned knowledge of 'what it is' and the cause of the condition, as parents whose children were as yet undiagnosed were unable to determine the correct courses of action for minimising symptoms. One mother explained that her son had suffered from pain and tiredness in his legs for over a year without them knowing how to resolve his problems, before finding out that he had a vitamin deficiency.

*"His bones, at night-time he used to feel tired and not move around his legs. He used to have this problem with his legs... We didn't know about vitamin D problem, but he had this problem a year or two maybe." (P16)*

Participant P02 encapsulated this point in her statement about the importance of healthcare appointments for finding out "what's wrong", "what to do" and "how to do it" (P02).

### 'Expert' medical knowledge

The third point about 'knowing' was demonstrated by several participants who exhibited significant medical knowledge related to their children's health conditions. Some parents used specialised medical terminology to describe illnesses, investigations and treatments, while others discussed the

biological causes and detailed mechanisms of specific health issues. For example, participant P12 conveyed an easy familiarity with the specialist terms for her daughter's rare chromosome disorder.

*"It's now called Kleefstra Syndrome. It's recently just been named that, but before that it was 9Q34.3 Deletion Syndrome."* (P12)

Likewise, interviewee P10 explained the treatment her son received in hospital after a severe asthma attack, including the particular term for the health setting, the drugs, and method of drug delivery, as well as the chemical effects of the treatment.

*"He was in HDU [the High Dependency Unit] for a long time with it. He had to have intravenous aminophylline to help him breathe and hydrocortisone through IVs and then those drugs affect the potassium around his heart, and his heart was beating too fast then he had to have potassium."* (P10)

In two cases this knowledge may have been facilitated by the participant's professional experience, having been employed in healthcare positions. For instance, participant P03 had worked as a nurse in paediatric care and frequently referred to a medical indicator of child development, *"the centiles"*, when discussing her son's failure to gain weight. However, much of this kind of specialist medical knowledge was expressed by interviewees whose children had long-term, rare or serious conditions, such as the aforementioned chromosome disorder and severe asthma. Parents of children with conditions that were not so all-encompassing did exhibit some specialist knowledge, but less comprehensively than participants with the most serious health issues. Participant P02, for example, used medical language to describe her daughter's conditions and investigations, including *"global developmental delay"*, *"febrile fits"* and *"EEG scans"*, but did not use the same specialist terms to describe treatments, saying instead *"they had to put something up her bottom"* (P02).

There was one divergent case to this pattern, as one parent whose child had a long-term, serious and rare condition showed less comprehensive specialist knowledge than other participants in similar situations. Interviewee P06 expressed excellent understanding of the timing and dosage of the dietary requirements she had to monitor.

*"She's only allowed so much protein a day. So she's allowed four exchanges, and an exchange is say, 45 grams of chips, 30 grams of ice cream."* (P06)

However, she was far less knowledgeable about the labels and workings of the condition itself.

*"She has PKU. I don't know how to say the proper one, phenylketonuria or something. And um, she's got too much protein in her body. And it doesn't break down or something so she has to have... this gel."* (P06)

The difference exemplified by participant P06 may be explained by the ways in which this type of specialist knowledge is used by parents in controlling their children's health conditions. As one might

expect, greater familiarity with medical terminology and biological mechanisms enhanced participants' perceived ability to control their child's symptoms and increased their feelings of being 'in control'. To illustrate, participant P10 described learning about different asthma medications and using this knowledge to exert influence over healthcare professionals at the emergency department in order to best control her son's symptoms.

*"When we was going through to A&E, you'd see one [doctor] and then you'd see another who would change the medication... And I'd have to say, 'Well actually, have you tried, with his inhalers he used to have salbutamol'... And then when he had the nebulisers they'd put atrovent in it as well, which really, really helped, and then I'd find myself saying to the doctors, 'If you put some atrovent in there, it might help.'" (P10)*

This excerpt demonstrates the advantages of obtaining specialist medical knowledge for parents being able to control their children's health issues. In contrast, participant P06 reported significant healthcare professional input from the BCH dietetic service and PKU team in the daily management of the child's condition. While the parent was in charge of ensuring that the child took the medicine and adhered to the prescribed diet, decisions around preventing symptoms and reducing impact of the condition were relayed to the clinicians at the hospital.

*"Because I don't know what I'm going about, I don't. To this day I even phone up my dietician, 'Oh I've got these crisps or whatever, can she have this?' And I read out the ingredients, and the protein and she'll say, 'Yes, no, yes, no.' And I've phoned her on a Sunday at like nine o'clock... I've got the number on my mobile, all I have to do is do the number, read in what I have to do." (P06)*

As such, the health issue was well controlled and the parent described relatively 'easy' management by calling on the dieticians' judgement whenever necessary. It's therefore possible that there was less need to obtain specialist understanding to be able to control the health issue, as professional knowledge and reliable symptom control were readily available from the healthcare professionals.

#### Sources of knowledge

These three types of knowledge - knowing what the condition 'is' in terms of cause and diagnosis knowing 'what to do' to manage the condition, and knowledge of specialist terminology and biological mechanisms that enhance parent's control of the condition – were obtained by participants from several different sources. The primary source mentioned by interviewees was information provided by healthcare professionals. Hospital clinicians identified illnesses and explained symptoms, gave management advice and shared medical phrases with parents. This was also an active process, as participants described both receiving and seeking information from healthcare professionals in order to control their child's condition.



*“Sometimes there's so many questions like... ‘What am I doing wrong? Why is she still ill? I'm doing everything they're telling me to do, what else can I do?’... You just don't know, so sometimes I have loads of questions to ask the consultant.” (P13)*

Participants also talked about obtaining knowledge important for controlling conditions through tests and investigations administered by the healthcare professionals. For example, one mother discussed the need for an allergy testing appointment so that the specific allergies could be identified, and therefore appropriate management strategies could be implemented.

*“I wanted to give him the proper food and we didn't know which kind of allergies he has, so we want to know which kind of the food he can have and which kind of food he cannot have. For that reason we ask for the allergy appointment, to know the allergy.” (P17)*

In addition to these direct sources of knowledge through the child's healthcare provision, participants also frequently sought information from alternative sources, including the internet, NHS advisory telephone lines, condition-specific online forums and conferences, and other parents. Interviewees mainly discussed accessing these alternative points of information when the diagnostic or therapeutic advice provided by the healthcare professionals was perceived as insufficient. For instance, participant P22 described speaking with other parents in order to figure out the cause of her son's illness, and participant P07 used different sources of information to find out about managing her daughter's coeliac disease.

*“There wasn't a lot of talk about coeliac disease so I really had to get on the internet and find out as much as I could about it and then join up with all the different [gluten-free brands] Glutafin, Juvela and all those, and try and go to some of the meetings they did. They had the big one in [town]. There was big convention there, we went to that one.” (P07)*

Participants also talked about using knowledge from their own personal experiences or those of close family members to help with understanding and managing their children's health conditions. Both interviewee P09 and P20 had experience of the same conditions that their children had now been diagnosed with (food allergy and epilepsy, respectively), and used this knowledge to recognise symptoms and direct management strategies.

*“They [the GP and health visitor] said that it was just startleness every time she kept waking up and I said, ‘It isn't, because I've got epilepsy.’ I said, ‘It's not.’” (P20)*

Several other parents mentioned relatives of the child having been diagnosed with the same condition, and drew upon their knowledge of this person's experiences to understand the illness. For example, participant P03 understood the cause of her son's limited growth by considering the experience of the child's uncle.

*"I think my husband's brother was also small for his age for a long time so we're guessing it's just genetics and then, yeah maybe he'll just shoot up to be six foot as well in a few years!"*  
(P03)

Intimate knowledge of the child, 'as a parent'

In contrast to the three types of 'factual' knowledge outlined above, the final type of knowledge discussed by parents was an experiential, personal and close understanding of their child. This knowledge was exemplified by expressions like, *"As a parent you know. You just know."* (P22). Participants emphasised close parent-children bonds that produced this kind of knowledge, using phrases such as 'my child' to stress intimate relationships. Parents relied on this interpersonal knowledge to manage health conditions by identifying when something was 'wrong' with their child and when the problem had resolved.

*"You know if there's something's up with your child. You soon pick it up."* (P20)

*"I know my daughter, I know she's fine."* (P04)

One parent highlighted that this intimate knowledge was exclusive to her as the child's parent.

*"So you don't know, she looks normal to anyone at school, but I know that she was tired and certain things had changed."* (P15)

These close bonds between parents and children often meant that when children suffered parents shared their suffering.

*"If she's not feeling very fine, technically I'm not very fine too. If she's fine and she's happy, then I'm fine, everybody's fine."* (P21, father)

This intimate 'felt' knowledge of their children's experience provided parents with a finely tuned sense of the child's health status, which was often used to inform healthcare decisions. For example, because of this 'just knowing' participant P20 persisted in seeking a referral to diagnose her daughter's symptoms despite primary care healthcare professionals dismissing her concerns.

*"Even if you haven't got help from doctors, or Health Visitors, you know [something's wrong]."* (P20)

This quotation illustrates that parents' experiential knowledge sometimes conflicted with the technical knowledge of the healthcare professionals. Participants P07 and P18 also reported occasions where they 'knew' something was wrong with their child, but struggled to convince clinicians whose medical insight suggested otherwise.

*“I said, ‘It’s not normal for a baby to breathe like that.’ So... they x-rayed her chest and it come back normal, and then he said to me some babies are born like that, they’ve just got this heavy breathing thing. So I was fine with that, but then I wasn’t fine with it and I kept pushing him and said, ‘Can you send her for some more tests? Because I’m not happy with it.’” (P18)*

This parent-child connection was also thought to operate in the opposite direction, with children being affected by the attitudes of their parents.

*“If I’m not happy, [child]’s not happy. And I’m sure that’s all your research shows, if a mum’s not happy, the child isn’t. If I’m confident, I can then instil confidence in him.” (P22)*

This participant observed that parental influences affected children emotionally and, in older children, could also affect healthcare decisions. For example, her son’s choice not to speak to a BCH paediatric psychologist may have been influenced by her own attitudes towards this service.

*“I could have perhaps approached it in a more positive light with [child] and said, ‘Well I think it would have been nice for you to talk to somebody.’ And this is where I think as a parent you do have a big influence on your children. But I wasn’t convinced it was necessary, it was too far down the line. And I didn’t like the idea.” (P22)*

#### Theme summary

Appointments were believed to provide the majority of the elements necessary for controlling children’s health conditions and were therefore perceived as extremely important. By attending appointments participants benefited from the provision and monitoring of medicines, delivery of tests and assessments to elucidate the cause and type of condition, the provision of advice for managing symptoms and for managing child behaviour, shared professional knowledge of illness labels and mechanisms, opportunities to ask questions of the hospital consultants, and opportunities to share parental knowledge of the child. Facilitating control through these means was the most common reason given by interviewees for appointment importance. All of these potential ‘gains’ of appointments contributed to the value of clinic visits for parents, and to their motivation to attend. This has implications for return appointments scheduled for routine follow-ups or ‘check-ups’ of children. If these appointments are not perceived to actively contribute to controlling a child’s health issue, it is less probable that they will be seen as important to attend and more likely they will be missed. Parents with children whose conditions were currently well controlled (especially those whose children’s conditions were not perceived to be particularly serious) had lower perceived *necessity* to go to the appointment, so lower motivation to attend and greater likelihood of non-attendance. In contrast, parents whose children had poorly controlled and serious conditions were more likely to feel a strong necessity to attend, so higher motivation and lower likelihood of non-attendance.

### **5.3.2.6 Theme six: Responsibilities as a parent and as a health service user**

Throughout their discussions of managing children's health conditions, overseeing healthcare, and attending hospital appointments, participants repeatedly explained their views and actions by referring to their identity 'as a parent' and the rights and obligations felt to be associated with this position. Interviewees also presented their views as considerate users of the General Paediatric service, expressing responsibilities towards other families using the service, healthcare providers, and the National Health Service (NHS). These perceived responsibilities were seemingly affected by personal and social influences, and played a significant role in participants' decisions and behaviours related to their children's healthcare, including attendance at appointments.

#### Parental responsibilities

Interviewees' beliefs about being a parent were apparent through statements about themselves as parents, about parenting in general and what parents 'ought' to do, and about their opinions of other parents' behaviours in relation to their children's healthcare. In addition to verbally positioning themselves "*as a parent*" (P07, P13, P22), participants exhibited their parental identity by talking about attempts to be a good parent outside of the healthcare context, including references to teaching children "*good things*" (P02), protecting them, and enforcing discipline.

*"[With] three boys, you've got to have a bit of discipline as well!"* (P22)

Some interviewees presented their personal parental values by making comparisons with other parents.

*"I know there are families out there that let the kids play out when they're five years old till ten o'clock at night when they should be in bed, but every parent's different I suppose and you can't tell somebody that what they're doing is right or wrong. You just have to do what's best for you've got."* (P04)

*"Without sounding nasty, some of the people you see at the hospital, just the way they treat their kids is just horrible. You can tell they're not really bothered."* (P13)

Others demonstrated their commitment to parenting through comments prioritizing the child or children within their lives. For example, parents stated that "*kids come first*" (P19), "*[child] comes number one*" (P20), and that the child was "*on the top list of everything*" (P02). Participant P12 went so far as to say:

*"My children are my life."* (P12)

This prioritization of the child was accompanied by an equivalent prioritization of the child's health.

*"At the end of the day, it's her health and that's a priority."* (P19)

*“Their illness comes first. Other stuff can wait.” (P20)*

*“I think as parents you like to know that your kids are healthy and safe.” (P10)*

As a consequence of the importance placed on child health, this identity as a dedicated parent was accompanied by an overarching responsibility to protect and promote children’s present and future wellbeing. This meant striving to minimize the impact of children’s health conditions on their physical functioning and quality of life, and obtaining the necessary healthcare to facilitate this. This perceived responsibility was made evident in many aspects of participants’ talk about their children’s healthcare. Specifically, interviewees emphasised parental obligations to actively pursue healthcare and to attend scheduled hospital appointments.

#### Actively pursuing healthcare

Participants highlighted a parental duty to actively seek healthcare for their children in order to relieve symptoms and resolve health conditions as quickly as possible. This included behaviours that went beyond a passive acceptance of care, for example being “*pushy*” (P22) in seeking an accurate diagnosis. Interviewees discussed researching potential problems and directly requesting referrals from GPs, looking for second opinions when GPs were felt to be obstructing care, and chasing up anticipated appointments at the hospital.

Requesting a referral: *“I tend to diagnose the kids’ problems and then bring them to the doctor [GP] and go, ‘Would you be able to refer me to this? Because I think my child’s got this.’ They’re not very happy, it’s like you’re trying to tell them their job. But as a parent if you think there’s a problem you’ve got to take it on yourself, you can’t just sit back and just go, ‘Oh well, he’s saying it’s not so maybe I should just leave it.’ Because that’s my child at the end of the day and I want to make sure that this condition’s nipped in the bud now rather than later.” (P07)*

Seeking a second opinion: *“[My friend] had to pursue it herself to try to get referred... To go and see another GP. Because the first GP that she saw wouldn’t treat her child... There was no prescription or anything involved, it was literally just, ‘Give him this [holistic remedy] and we’ll see how it goes.’ If she hadn’t pursued it again obviously it could have caused problems for the child... But the parents themselves have to obviously want to pursue it and see that there’s an issue.” (P03)*

Chasing up appointments: *“If your child needs to be seen and you believe that that child shouldn’t be waiting then I would probably cause merry hell, but she has been seen and I’m grateful for that and she’s fine, so I’m a bit more relaxed as to chasing up to an appointment again.” (P04)*

These quotations highlight that responsibility to pursue care was heightened when children were experiencing symptoms and parents perceived there to be ‘an issue’. However, when children’s health conditions were resolved or under control this responsibility waned, as the aim to optimize child health was already being met. This suggests a gradient of responsibility where greater

symptoms and impact on the child (i.e. high severity) mean greater responsibility to find remedial healthcare.

#### Attending hospital appointments

Interviewees were generally insistent that parents should bring their children for scheduled hospital appointments regardless of difficulties. For example when asked about the challenges of going to the hospital, participant P11 noted that parents simply 'had to' accept the hassles of attendance.

*"When it comes to your child's health you got to make sacrifices. You have to make sure you attend these appointments."* (P11)

Other participants gave many examples of their willingness to tolerate the inconveniences of attendance for the sake of their children's health. Interviewee P04 commented that *"you don't mind the waiting time"* in the clinic when it was *"for your kids"* (P04), parent P10 remarked about having frequent appointments that, *"You don't mind do you, when it's the health of your child"* (P10), and interviewee P20 noted that she *"had to"* manage travel costs because her child's illness came first. Regarding clinic location, interviewee P14 expressed a preference for the outreach site at his local health centre, but noted that supporting his child's health through better facilities at the main hospital was more important than ease of travel to the appointment.

*"Easiest way to go [is to] to health centre. But if they don't have facilities, then it doesn't make sense to go health centre. Because it's more important that we look after our children, and our health."* (P14)

Finally, participant P13 emphasised that they would have attended their daughter's hospital appointment regardless of time, location, or impact on their family life in order to obtain the necessary care for their child and alleviate her condition, thereby fulfilling their parental responsibilities.

*"I would've still had to have gone in on my [other daughter's birthday]... We would've dragged her in if it was Christmas day I think... But some parents aren't like that unfortunately... We'd go to every one, at any time. Wherever it is. Because it's [child] and it's for her sake."* (P13)

Several interviewees additionally discussed whether the hospital or General Paediatric service also had responsibilities concerning attendance, either through preventing missed appointments or following up families who had not attended. Four participants considered that BCH should *"do something about"* (P16) 'did-not-attends' and *"try and reduce them as much as possible"* (P05) in order to prevent wasted resources and impacts on waiting lists, and to help parents who struggled with remembering appointments. These interviewees and many others were emphatic in their endorsement of appointment reminders. However, when it came to bringing individual children to

appointments five parents declared that the hospital were “doing enough” (P10) already by providing services and communicating with parents about appointments.

*“I think they only can do so much. They can’t really drag them [families] to their appointments, because they’re sending out reminders beforehand, which they don’t even really need to do that.” (P15)*

Moreover, participants believed that the hospital was unable to prevent families from missing appointments, and did not have the resources to follow up all children who did not attend.

*“What can they do if someone misses it? You can’t tell an adult what to do, can you? You either attend or you don’t.” (P06)*

*“We had one letter to say that we’d missed the appointment... The hospital can’t do any more than that. We’re not the only person there they’ve got missed appointments for and chasing appointments.” (P04)*

These interviewees emphasised that attendance was “up to the parent” (P04), laying the responsibility firmly with individuals rather than the hospital.

*“I think it’s up to the patients themselves to sort it out really. Because if they’re given an appointment they shouldn’t really miss it... Because the hospital do their job, they send the appointments out.” (P18)*

#### Factors influencing perceived parental responsibilities

Participants’ beliefs about responsibilities were reinforced by two additional factors: socially-imposed parental obligations and a perceived need to act on behalf of the child.

#### Social aspects of parental responsibilities

First, interviewees’ perceptions were informed by societal expectations of parental responsibilities. Two participants observed that parents were in charge of making healthcare decisions until their child was *legally* old enough to be responsible for their own healthcare, either at sixteen or eighteen years of age.

*“It’s the parents’ [responsibility] at the end of the day because they’re kids. They’re not legally responsible until they’re sixteen. So you’ve got to make the decisions for them whether they want to go [to the appointment] or not, it’s immaterial. It’s up to the parents to make sure that they are there.” (P19)*

Similarly, two participants believed that if parents failed in their obligations to provide healthcare then they were not meeting societal standards for parenthood and there should be social consequences. Both of these interviewees advocated the involvement of social services if parents did not bring children for hospital appointments.

*“If I’m at a point where I’m not able to take her to appointments there’s something wrong, socially for me... I think it should be, if somebody’s getting repetitive missed appointments, that it’s something social services pick up... You’re there to care for a child, and even through you’re the parent and you’re the decision-maker, there’s still a reason why that child should be seen by a doctor. It’s not for no reason. So are you caring for that child?” (P12)*

*“If you’re not prepared to take your kids in, get social services involved because at the end of the day you’re not taking the best care of your kids!” (P19)*

It should be noted that both of these parents were employed or previously employed in professions allied to healthcare (parent P12 had worked as a mental health support worker and was now a ‘care manager’, and parent P19 had worked for many years as an ambulance driver). Consequently they may have had stronger opinions regarding social responsibilities for healthcare.

In contrast, interviewee P06 did not openly endorse the involvement of social services, rather she reported having been told by the dietetic team at BCH that failure to manage her daughter’s diet and medications properly would result in the child being ‘taken off her’ by social services.

*“They’ve said to me, ‘If you started feeding her the wrong diets we wouldn’t hesitate to phone social services and have her took off you.’... There was two [children] and the Mum didn’t follow the diet, she went off the diet, didn’t give her the gel. They were took off her, they’re in foster care now. It’s because it’s child abuse isn’t it. It’s like feeding her rat poison... It slowly poisons the brain... So you haven’t got a choice in life, you’ve got to do it.” (P06)*

Clearly this parents views on her responsibilities as a parent would have been deeply coloured by these explicit obligations imposed by the health service.

As a result of these social influences, participants had to uphold their parental responsibilities not only to achieve their own aims, but because they were accountable to healthcare professionals and wider society. Thus, although they were *responsible* for ensuring the child attended their scheduled appointments (in that it was their perceived duty to do so), this did not necessarily mean that parents felt they had the *right to choose* whether to attend or not. The combination of parents’ self-imposed obligations and perceived social expectations resulted in four participants remarking that they had ‘no choice’ but to attend their children’s appointments, or that missing appointments was “*not an option*” (P21).

*“We can’t say it’s a difficulty [to go to the hospital] because we have to go. Because once we get the appointment we need to go.” (P14)*

There was one obvious exception to this viewpoint. Participant P04 had expressed strong opinions that parents had a duty to bring their children to appointments when those children needed to be seen for diagnosis or treatment. However, she highlighted that when children’s conditions were resolved and appointments were no longer crucial then parents could afford to be “*a bit more slack*”



(P04) about pursuing healthcare. As such, this interviewee held associated views that parents should have the authority to decide whether or not to bring their children to the hospital.

*“I think also it’s a parent’s wrong and a parent’s right to say, ‘I don’t want my child to come all the way to hospital because she is absolutely fine, I take responsibility for this.’ I think as a parent you have to make the decision.”* (P04)

It was apparent however that although this participant believed that parents should have the right to choose whether to attend, this right was not put into practice. She stated that she would be *“quite happy”* to telephone her child’s consultant and say that her child was *“absolutely fine”* (P04), yet she still planned to attend the next appointment even though it was no longer perceived to be necessary. Arguably this parent could have telephoned the hospital and cancelled the appointment outright, but instead desired a system whereby she could call the consultant so that the cancellation was agreed with the service.

*“It would be then the consultant’s or the secretary’s choice to say, ‘Ok well we don’t need to see her then, but thanks for letting us know.’”* (P04)

Not only does this highlight that hospital systems are not set up to facilitate the implementation of this right, it also illustrates the difficulty in giving parents the authority to decide: those parents must be able to tell definitively whether or not the appointment is necessary. Although this parent was confident that her child was now ‘fine’, the reassurance of the service providers was still desirable to ensure that the correct decision was made. In most other cases, participants believed that their children’s appointments were still necessary and would therefore *not* have this proposed right to decide about going to appointments, as a choice not to attend would constitute a failure of their personal and social responsibilities to obtain healthcare and to protect child health.

#### Acting on the behalf of the child

A second factor that contributed to participants’ perceived responsibilities was the need to act on behalf of their children because they were too young to be able to make appropriate health-related decisions for themselves. Some interviewees commented on the need to be in charge of daily management of the condition because of the child’s young age.

*“You have to be cruel to be kind to be quite honest, because she can’t do it herself obviously. She’s only six so I have to be the strong person in this and help her all the way.”* (P18)

As mentioned above, some parents envisioned acting in this capacity until the child was legally responsible for their own healthcare. Participant P06 remarked that her daughter would be entitled to come off her strict diet *“when she was eighteen”* (P06), but until then she would intervene regardless of age.

*“There was a fifteen year-old girl and she was sitting in front of her Mum and Dad, and she started eating a beef lasagne. And she’s not supposed to do that because that’s like deadly... Regardless of whether she’s five or fifteen, I would have grabbed it off her and threw it up the wall, and said, ‘What are you playing at?’” (P06)*

In some cases this stewardship of the child’s health was thought to be for the benefit of the child’s future adult self. For example, parent P18 commented prior to the statement above that *“it’s for her future at the end of the day”* (P18). Similarly, interviewee P21 hypothesised about her daughter’s wishes when she was grown up and resolved that missing appointments was not acceptable because they might facilitate *“a normal life”* (P21) in the future.

*“We’re thinking about when she’s older. She would want to do normal things like drive and maybe even live on her own, but how do you live on your own if you’ve got epilepsy?... Together hopefully we can cure it and she can have a normal life.” (P21)*

Other participants acted as advocates for their children’s health because their infancy rendered them ‘voiceless.’

*“It’s not the child that can talk and tell you what the problem is, so the parents have got to be on the ball and make the decision. It’s like her being put to sleep, she can’t sign the form to say, ‘Put me to sleep’, it’s got to be mum and dad who decide and sign the form to say, ‘Yes, go ahead.’ So we’re her voice really.” (P13)*

Again, the responsibility of participant P04 to pursue healthcare was diminished compared to other interviewees, in this instance because the child was old enough to confirm that the condition was well controlled, thereby lowering the necessity of the appointment and the parent’s obligation to attend.

*“A fourteen year-old that can speak her own mind, that can tell you what’s wrong, is different from a two year-old that that can’t speak for themselves. But when you’ve got an older teenager that says, ‘You know what Mum, I’m absolutely fine.’ She does tell me if she’s in pain.” (P04)*

#### Responsibilities as a health service user

In addition to their perceived responsibilities as parents, interviewees also shared views suggesting perceived responsibilities as considerate users of a health service. These responsibilities were expressed as behaviours that parents ought to carry out for the benefit of the service, the service providers or the other users of the service. Some of these behaviours related to the experience of families within the clinic setting. For example, participant P13 asserted that attending families should bring only a limited number of additional people so as not to take up space in the waiting area, and spoke of rushing their own consultations so as not to make other families wait any longer than necessary.

*“Some people they have an appointment for one child... come with four kids to the hospital and you think all four can't be being seen. And a mother and a grandparent, and they take all the seats up. And sometimes you have to stand. And it's like a cattle-shed really. It's not right, I don't think. They should maybe even limit two people with you. I don't see why there should be a family of seven.” (P13)*

*“You are almost pressured to know that there's so many people waiting outside. And you come out thinking, ‘Oh, I didn't ask this and I didn't ask that’, because you're rushing because of others. Because you've just waited for like an hour and you don't want to put them under waiting any longer.” (P13)*

However, the majority of data related to this topic was regarding the responsibility to attend children's outpatient appointments. This responsibility was predicated on three potential consequences of non-attendance: the impact on other families waiting for appointments, the impact on the consulting healthcare professional, and the impact on the health service.

#### Potential impact on other families

Interviewees were particularly concerned with possible effects on other parents and children waiting to be seen by the General Paediatric service. Seven participants mentioned the “vital” (P06) importance of attending rather than missing clinic visits because otherwise the appointment could have gone to a child “who needed it more” (P07).

*“It's not very fair on other patients that need that appointment.” (P08)*

*“You've got people that are desperate to get in to see a consultant for something and they can't, but you get idiots that don't turn up and aren't bothered.” (P19)*

One participant thought that non-attendance might actually be advantageous for waiting families, but nonetheless disapproved of missing appointments due to other potential effects.

*“It might be problematic for the doctors because they make their time, but otherwise sometimes it's good for the other families who need the appointment more, and then somebody who's missed the appointment, they can catch that time.” (P17)*

#### Potential impact on the healthcare professional

There was also a perceived need to attend so as not to negatively impact on the consultant providing the hospital appointment. For example, parents saw non-attendance as “wasting doctor's time” (P21) and “not good for [the] doctor” (P14). Two interviewees spoke about their personal views and experiences of missing appointments and the impact on the healthcare professionals.

*“I hate missing appointments anyway. I like to make sure I make all my appointments so I don't let anyone down.” (P07)*

*"I got the date wrong. Totally wrong. I was so devastated... Because she could've been sat there waiting for me... and no communication to even know why we hadn't turned up. That's so bad because it's her time that she's taking out for us. Because I know how busy they are, you don't want to take up their time and miss appointments, it's really important." (P13)*

#### Potential impact on the health service

References were also made by four participants to the financial and material consequences of missing appointments.

*"I mean at the end of the day it's a waste of how much resources?" (P19)*

*"I think it is a drain really on the National Health [Service]. So yeah I do think it's quite a serious thing." (P12)*

Again, these two interviewees who gave the clearest indication of responsibility towards the health service were both previously or currently employed in health-related professions and so may have had more insight into potential consequences for the service when families did not attend. This responsibility for protecting the health service was associated with an appreciation for healthcare provision both locally and nationally.

*"I think we're quite fortunate to have a hospital for children, a specialist children's hospital, and which is so convenient for us as well in Birmingham." (P11)*

*"I don't think people realise the extent of what we've got in England when it comes to the NHS and the Children's Hospital, and every member of staff that's involved in the process of your child getting appointments, going into hospital, how much hard work goes into it... People don't see it for what it is really. And it's a service that people should be more appreciative of." (P12)*

#### Theme summary

This theme has demonstrated that participants were motivated to attend in order to fulfil their responsibilities as parents and as considerate health service users. Perceived obligations to attend were both socially imposed and generated through interviewees' self-identities. Participants prioritized children's wellbeing and expressed desires to fulfil parental responsibilities by attending appointments in order to best promote child health.

## **5.4 DISCUSSION**

### **5.4.1 Summary**

This study sought to elucidate parental cognitions associated with attending and missing General Paediatric hospital appointments by examining their reported views, beliefs and experiences. The

thematic framework analysis generated six themes which answered this research aim. The major themes and sub-themes are presented in table 12.

**Table 12. Summary of major themes and sub-themes**

<b>Theme No.</b>	<b>Theme title and sub-themes</b>
<b>1.</b>	<b>Planning and managing appointments</b> Appointment letters and reminders Perceptions of appointment reminders Strategies for remembering appointments Fitting appointments around other aspects of the family's daily life Telephoning the hospital
<b>2.</b>	<b>The experience of attending appointments</b> Travelling to the clinic The clinic environment 'Knowing what to expect' in the outpatient department Managing children
<b>3.</b>	<b>Evaluations of healthcare</b> Relationships with General Paediatric consultants Beliefs about specialist paediatric healthcare
<b>4.</b>	<b>Perceived seriousness of the child's condition</b> Impact on the child's physical functioning and wellbeing Impact on the child's social and emotional wellbeing Frequency and severity of symptoms Comparing the child's condition with others Information from healthcare providers
<b>5.</b>	<b>Controlling the condition</b> Factors that help or hinder control Beliefs about controlling conditions through medication The importance of knowledge for controlling conditions
<b>6.</b>	<b>Responsibilities as a parent and as a health service user</b> Parental responsibilities Factors influencing perceived parental responsibilities Responsibilities as a health service user

The first theme highlighted the difficulties that parents experience when planning visits to the hospital. Some difficulties were hospital-generated, for instance errors and poor timing of appointment letters and poor telephone communication facilities, while others were related to the individual family, for instance taking time away from work and school. However, facilitating factors were also mentioned, including the use of appointment letters as negotiating tools and strategies for remembering appointments. These issues increased or decreased families' ability to attend.

The experience of attending appointments was also characterised by difficulties and factors that made attending stressful, including complex journeys, costs associated with clinic visits, the surroundings and perceived cleanliness of the outpatient department, unspecified waiting times, and managing children's behaviour. Perceived stress from each of these factors contributed to parents' perceived ability to attend appointments.

Perceptions about the care delivered by health care professionals were also important, and were evaluated in terms of 'quantity' (e.g. frequency of appointments, availability of the clinician outside of the appointment time, duration of clinic visits with the doctor) and 'quality' (e.g. perceived competence, child-friendliness, and perceived empathy and support). Parents also had beliefs about the superiority of specialist children's health care in comparison to GP care and care provided by other hospitals. Specialist care was valued as parents believed there to be greater expertise and more resources available at BCH. This valuing of specialist care and the perceived relationships with consultants led to greater motivation to attend.

Additionally, it was found that parents hold beliefs about the seriousness of their children's health issues, which include perceptions about the impact of the condition on the child's social and physical wellbeing, and the risk of serious outcomes, including mortality. These beliefs were influenced by the perceived frequency and severity of symptoms, comparisons with other children or conditions, and information from health care professionals. Appointments were therefore important to attend in order to obtain information from the health care provider about the seriousness of the health issue, and for reassurance that their own parental judgements of seriousness were accurate.

Parents discussed their experiences of controlling children's health issues and the factors that made management easier or more difficult, such as complexity of the regimen, child behaviour, and support from the child's school. Parents discussed concerns about reliance on medicines, but these were outweighed by the perceived benefits of controlling symptoms. Different kinds of knowledge were extremely important for parents feeling able to control their children's health, including knowledge about diagnoses, causes, treatment and management requirements, and relevant medical terminology. Experiential 'knowing' of their children was also important for gauging children's health needs. Attending appointments was therefore perceived as important for obtaining the knowledge necessary to effectively manage children's health issues.

Finally, parents expressed strongly-held feelings of responsibility as parents to protect and promote their children's health by actively pursuing health care and attending appointments. Perceptions of parental responsibility were influenced by social expectations about parenting and a perceived need

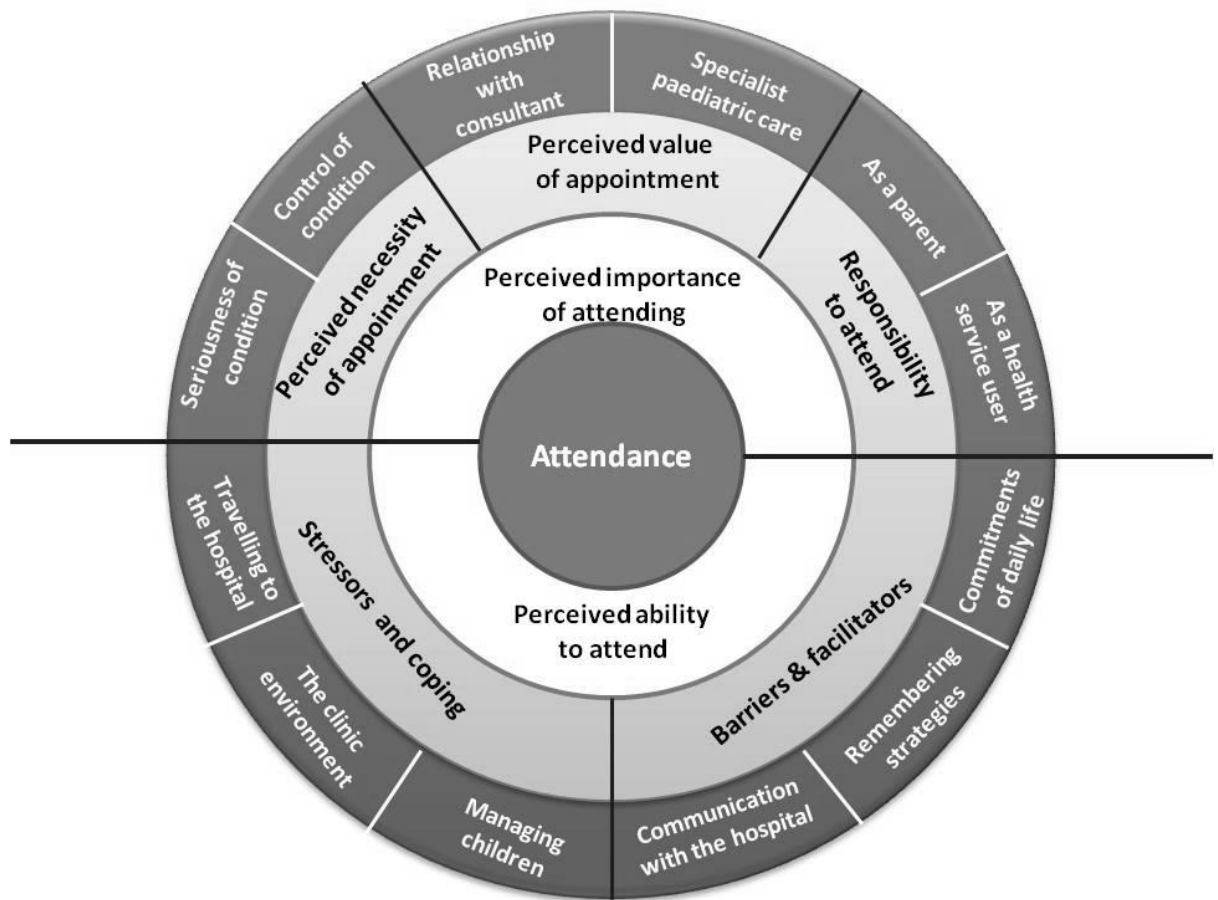
to act on behalf of the child. Perceived responsibilities as health service users were also present in the data, but were not as strongly emphasised as parental responsibilities. Health service user responsibilities stemmed from perceptions about impacts on other families, on the health care professional, and on the health service in general. Parents were therefore motivated to attend in order to meet their responsibilities, primarily as parents, but also as users of a health service.

#### **5.4.2 Theory development**

The findings described above cluster around two main concepts. First, parents' perceived *ability* to attend which comprises perceptions about the stress of travelling to the clinic, being in the clinic, and managing children, and perceived barriers and facilitators to attending, including communication with the hospital, remembering strategies, and other commitments of family life. Second, the perceived *importance* of attending in order to determine seriousness, to obtain knowledge to control the condition, to maintain relationships with health care professionals, to receive valued specialist care, and to meet responsibilities as a parent and as a health service user. These two overarching concepts are presented in an illustrative diagram (figure 3) in order to show the two aspects of parents' beliefs illuminated by this study. However, the diagram is not intended to represent a formal theoretical model, as the full range of ways in which the constructs interrelate have not yet been explored and it is likely that some constructs would be more heavily 'weighted' than others. For example, perceived responsibility as a parent would likely have more influence on behaviour than perceived responsibility as a health service user, and perceived seriousness of the child's illness might be one of the most crucial factors. These weightings and relationships should be tested in further research, though it is clear from the findings of this qualitative study that all of the expounded cognitions have some role to play in attendance and non-attendance.

The two main concepts, perceived importance of attending and perceived ability to attend, have similarities with the two central constructs proposed by Horne and Weinman (1999; 2002) in their theory of beliefs about medication. These authors proposed that, "*adherence decisions are influenced by a cost-benefit assessment in which personal beliefs about the necessity of the medication for maintaining or improving health are balanced against concerns about the potential adverse effects of taking it.*" (Horne & Weinman, 1999, p. 557). The same statement could be claimed regarding parental decisions about attendance, with beliefs about importance of attending counter-balancing concerns about negative consequences of attending. Other authors have recognised the similarities between adherence to medication and attendance at appointments, with

**Figure 3. Illustrative diagram of qualitative findings**



several systematic reviews treating attendance as a particular form of adherence (e.g. Roter et al., 1998; van Dulmen et al., 2007). However, no studies have tested Horne and Weinman’s necessity and concerns framework with attendance behaviour, and many items on the Beliefs about Medicines Questionnaire (BMQ) (Horne & Weinman, 1999) would not be applicable to attending appointments. For example, items measuring worry about becoming dependent on medicines or medicines being a ‘mystery’ are unlikely to be relevant.

Horne and Weinman (2002) also advocate that beliefs about medicines are operationalized as part of an extended Common Sense Self-Regulation Model (CS-SRM) (Leventhal et al., 1998; 2003). The CS-SRM describes five ‘illness representations’ proposed to influence coping behaviours, including beliefs about the cause, consequences, cure (or control), timeline and identity of an illness. Some aspects of the qualitative findings from the current study may be usefully explained by illness representations. For instance, findings related to controlling the condition have clear links with the ‘cure/control’ illness representation and some beliefs about seriousness of the child’s condition may



be described by the consequences and timeline constructs. However, there remains several aspects of the qualitative findings unaccounted for by either the necessity and concerns framework, or illness representations as part of an extended CS-SRM. The perceived value of receiving specialist paediatric care, for example, cannot easily be described using constructs from these models. Consequently, further theoretical work is required such that non-attendance at paediatric outpatient appointments can be sufficiently predicted and explained by all of the relevant parental cognitive factors elucidated here.

#### **5.4.3 Relationship to the literature**

Many of the findings regarding parents' perceived ability to attend appointments expand on findings from observational studies that report non-attendance as related to problems with accessing services, communicating with services, forgetting appointments, and managing clinic visits alongside daily life. However, the qualitative findings presented here provide new, in-depth information about the lived experience of each of these issues, and the ways in which they operate to affect attendance. For example, McClure et al. (1996) found that longer journey times and travel by public transport or walking rather than by car was associated with non-attendance, while Cordiner et al. (2010) reported that greater distance to clinic was related to more missed appointments in a Community Paediatric sample. Simple interpretations of these results might suggest that appointments are missed because journeys are inconvenient for parents or because they constitute significant practical barriers. The findings from the current qualitative study go beyond this understanding however to highlight the many aspects of travel that contribute to the anticipated stress of attending, including the complexity of the journey, the cost of travel, and difficulties travelling with children who are unwell.

The findings also expand upon the often cited reason for missed appointments, 'forgetting' (e.g. Andrews et al. 1990; Gatrad, 1997). It is apparent from this study that in fact parents go to great lengths in their attempts to remember appointments, using many different strategies, but non-attendance can result when their intended strategies fail, or through remembering incorrect details rather than merely forgetting entirely. Similarly, the findings corroborate survey reports that some appointments are missed due to communication errors on the part of the hospital (Andrews et al. 1990; Gatrad, 1997). The finding that parents find it difficult to manage appointments around work, school, other children and other aspects of daily life demonstrates that a high level of organisational skill may be required in order to attend appointments. This may somewhat corroborate the views of healthcare professionals that appointments are missed by 'disorganised' families with 'chaotic' lives (chapter four). However, this is unlikely to be a fair and whole assessment given all of the factors

experienced by parents managing children with health conditions, and further research is required to develop a framework where this issue is seen in relation to other influencing factors. Other aspects of parents' perceived ability to attend, including perceptions of the clinic environment and anticipated difficulties in managing children, appear to be novel findings that contribute new understandings to the literature about factors that decrease motivation to attend appointments.

Findings related to the perceived importance of attending are also supported by prior research. For example, the finding that parents perceive appointments at a specialist paediatric healthcare centre to be more valuable than those provided in general hospitals or by GPs, accords with findings reported in a meta-analysis by Cooke and French (2008) that for patients invited for health screening appointments, intention to attend was far more predictive of attendance when participants were recruited via hospital settings than through health authorities or GP practices. Similarly, parents in this study indicated the importance of relationships with the consulting healthcare professional as a factor in motivation to attend, which was also mentioned by adult patients in regards to primary care services in a previous qualitative study though the importance of this aspect appeared to be under-appreciated by GPs (Martin et al., 2005). As mentioned in the previous section, aspects of perceived seriousness and control of the child's condition relate to illness representations described in Leventhal et al.'s (1998; 2003) Common Sense Self-Regulation Model. Although there have been studies applying this model to adult attendance at health-related appointments (e.g. Hagger & Orbell, 2005) and to parents' perceptions of child illness (e.g. Peterson-Sweeney et al., 2007; Ringlever et al., 2012), no research has yet examined the application of this theory to parental perceptions and attendance at children's healthcare appointments. Again, there are also aspects of parental perceptions of importance to attend appointments that present novel issues not yet considered in the literature, such as how beliefs about personal responsibility affect motivation to attend appointments.

#### **5.4.4 Strengths and limitations**

This qualitative study was the first to examine parents' beliefs and experiences of attending and missing children's hospital outpatient appointments, and provides the first evidence of factors aside from forgetting and practical barriers that are important in determining attendance behaviour. One limitation was that the majority of data coding and analyses were conducted by just one researcher. However, transcripts and early coding were shared with doctoral supervisors, and discussion with the supervisory team was important in refining the final coding framework which was applied to the whole data set. The study benefitted from a diverse sample of parents, including a range of ages, ethnicities, social circumstances and conditions for which their children were referred to the General

Paediatric service. Caution is required in applying the findings presented here to other settings and patient groups, however the study highlights many issues that are likely to be relevant across healthcare services.

#### **5.4.5 Conclusion**

This qualitative study of parents' views and experiences of attending and missing General Paediatric outpatient appointments has highlighted that there are many factors potentially associated with motivation to attend appointments and attendance behaviour that have not yet been considered in the literature. These factors appear to centre around two main issues: parents' perceptions of the importance of attending, and their perceptions about their ability to overcome difficulties and stressors to attend. However, further research is required to develop methods for analysing these issues quantitatively and to examine the ways in which the identified factors relate to one-another when assessed statistically. The following chapter will begin the work of developing these findings into a working model of attendance behaviour, by developing a measure of parents' beliefs about attending and investigating the factor structure underlying these beliefs.

## CHAPTER SIX

### 6. Questionnaire study to identify the factors underlying parents' beliefs about attending appointments

#### 6.1 INTRODUCTION

The previous chapter described a qualitative study which was the first to elucidate parents' perceptions about attending and missing children's hospital outpatient appointments. The findings highlighted many issues that have not yet been considered in the literature, and which now require assessment using quantitative methods in order to facilitate the development of new theoretical understandings of parental attendance behaviour. The aim of the questionnaire study was therefore to investigate the underlying factors that explain and structure parents' beliefs about attending children's General Paediatric outpatient appointments. To achieve this aim the specific objectives were to design a questionnaire to measure appropriate cognitive variables, to conduct a survey of parents using this questionnaire, and to implement an exploratory factor analysis on the collected data to understand the structure of parental beliefs.

#### 6.2 METHODS

This section describes the methods used to design, administer and analyse a quantitative questionnaire of parents' cognitions about attending an upcoming scheduled outpatient appointment. The planning and implementation of this study were guided by the stages of survey research design outlined by Oppenheim (1992, p.7), including conceptualization, defining research questions and specific variables to be measured, designing the research instrument, pilot testing the questionnaire, designing and selecting a study sample, collecting data, analysis and assembling results. The ways in which these procedures were carried out will be reported in the following two sections.

##### 6.2.1 Designing the questionnaire

The content, format and presentation of the questionnaire were developed in accordance with training provided by the ESRC National Centre for Research Methods and the University of Southampton (Campanelli, 2012).

### **6.2.1.1 Determining which variables to measure**

#### Cognitive variables

Field (2013) notes that to produce a stable factor solution in an exploratory factor analysis, “*a wise researcher will measure enough variables to measure adequately all of the factors that theoretically they would expect to find*” (p.684). This means that all aspects of the dimension of interest ought to be measured through a range of variables so that the most explanatory underlying factor structure can be elucidated and sufficiently supported, as a factor cannot be defined by just one measured variable. Thus it was necessary to measure a broad range of parental cognitions about attending appointments. As mentioned in the introduction chapter, previous research investigating parents’ beliefs about attending paediatric outpatient clinics has been extremely limited. The findings of the qualitative interview study with parents at Birmingham Children’s Hospital were therefore used as the primary source for determining variables to include in the questionnaire.

The findings of the qualitative study were reviewed for cognitions that influence beliefs about attending appointments. The listed cognitive variables were then mapped to constructs from existing health behaviour theories where possible. The mapping process is presented in table 13. In these instances the whole theories were checked for potentially relevant cognitions. If the theory contained other constructs that could reasonably be expected to have an effect on beliefs about attending and that were not already listed, these were also added to the list of variables. For example, the qualitative findings suggested that the constructs ‘attitudes towards attending the appointment’, ‘beliefs about the outcomes of attending the appointment’ and ‘perceived behavioural control over attending the appointment’ from Ajzen’s Theory of Planned Behaviour (1991) should be included in the questionnaire. This theory also includes the construct ‘subjective norms’ about attending the appointment, which is the perception of other people’s beliefs about performing the behaviour. This was added as a potential variable though there were only brief mentions of views related to this concept within the qualitative data. Cognitions that could not be mapped to whole theories were instead identified as individual theoretical constructs that have been previously tested in empirical studies, for example ‘perceived social support’ and ‘anticipated affect’.

It has been noted that when designing questionnaires that measure cognitions associated with behaviours, it is important that all items adhere to the ‘principle of compatibility’ (Ajzen & Fishbein, 1977). This principle states that measures of cognitions and behaviour should refer to exactly the same action, target of action, context and timeframe, and should be defined at the same level of generality or specificity. That is to say, it is necessary that predictor variables (e.g. beliefs) are

measured in reference to exactly the same behaviour that is measured by the outcome variable. If cognitive variables measured beliefs about attending appointments *in general*, and were tested against an outcome variable measuring attendance at a *specific* appointment, the predictive validity and cognition-behaviour correlations of these measures would be low.

Although the primary aims of this study were merely to explore the factors underlying beliefs, not to test predictive relationships of the measured cognitions, it was still important that all of the variables were designed to measure cognitions related to the same reference behaviour in order to maximise the common variance within the resulting data, thereby increasing the likelihood of producing a robust factor structure. This would also facilitate potential secondary analyses or future research using predictive methods, as the questionnaire and resulting factors could provide a foundation for hypothesis-testing studies.

Consequently, the questionnaire was explicitly designed to measure cognitions associated with attendance at an upcoming General Paediatric appointment scheduled within the two months following data collection. This specific behaviour adhered to the TACT (target, action, context, time) structure advocated in behavioural research (Francis et al., 2004).

<b>Action:</b>	to attend
<b>Target:</b>	the appointment
<b>Context:</b>	at the hospital / with the child
<b>Time:</b>	at the scheduled time within the next two months

Attendance at a specific appointment is the most likely outcome variable that would be used in future research, rather than attendance at all appointments or appointments in general, so this level of specificity was determined to be the most appropriate.

Items measuring the participants' intentions to attend the upcoming appointment were also included as it was hoped that secondary analyses for post-PhD publication may be possible in which the relationships between parents' cognitions, or the elucidated underlying factors, and intentions could be investigated. These items were not intended for inclusion in the factor analysis, as they measure a potential *outcome* of parents' beliefs about attending rather than a perception or attitude on the same level as the other questionnaire items.

**Table 13. Mapping cognitions to theoretical constructs**

Cognitions identified in each qualitative theme	Mapped theoretical constructs and theories
<p><b>Theme 1. Perceived seriousness of the health condition</b></p> <ul style="list-style-type: none"> <li>• Concern or worry about the condition</li> <li>• Perceived impact of the condition on the child’s physical functioning and wellbeing</li> <li>• Perceived impact of the condition on the child’s social and emotional wellbeing</li> <li>• Perceived frequency and severity of symptoms</li> <li>• Perceived importance of the appointment for determining seriousness</li> </ul>	<p><i>‘Emotional representation’ of the condition (CS-SRM)</i>  <i>‘Consequences’ illness perception (CS-SRM)</i></p> <p><i>‘Consequences’ illness perception (CS-SRM)</i></p> <p><i>Perceived health status of the child</i></p> <p><i>Perceived ‘necessity’ of the appointment (N&amp;C) / Attitude towards attending (TPB)</i></p>
<p><b>Theme 2. Controlling the condition</b></p> <ul style="list-style-type: none"> <li>• Beliefs about longevity of the health condition</li> <li>• Perceived ability to manage the condition</li> <li>• ‘Knowing’ about the condition</li> <li>• Perceived importance of the appointment for controlling the condition</li> </ul>	<p><i>‘Timeline’ illness perception (CS-SRM)</i>  <i>‘Personal control’ illness perception (CS-SRM)</i>  <i>‘Coherence’ illness perception (CS-SRM)</i>  <i>Belief about outcome of attending (TPB) / perceived ‘necessity’ of the appointment (N&amp;C)</i></p>
<p><b>Theme 3. Evaluations of healthcare</b></p> <ul style="list-style-type: none"> <li>• Perceptions of quantitative aspects of relationships with consultants (e.g. frequency of appointments)</li> <li>• Perceptions of qualitative aspects of relationships with consultants (e.g. competence, empathy)</li> <li>• Beliefs about specialist healthcare (e.g. experience, expertise, ‘specialness’)</li> <li>• Perceptions of GP care</li> </ul>	<p><i>Satisfaction with General Paediatric care</i></p> <p><i>Satisfaction with General Paediatric care</i></p> <p><i>Attitude towards hospital doctors</i></p> <p><i>Satisfaction with GP care</i></p>
<p><b>Theme 4. Planning and managing appointments</b></p> <ul style="list-style-type: none"> <li>• Perceived ability to remember the appointment</li> <li>• Perceived ability to take time away from work and other commitments</li> <li>• Perceived likelihood of assistance from spouse or family to manage other commitments</li> </ul>	<p><i>Self-efficacy / perceived behavioural control (TPB)</i></p> <p><i>Self-efficacy / perceived behavioural control (TPB)</i></p> <p><i>Perceived social support</i></p>
<p><b>Theme 5. Experience of attending appointments</b></p> <ul style="list-style-type: none"> <li>• Perceived difficulty of travel</li> <li>• Perceived difficulty paying for travel</li> <li>• Anticipated emotions in clinic environment</li> <li>• Perceptions of waiting in the clinic</li> <li>• Perceived difficulty of bringing child to the appointment</li> <li>• Perceived difficulty of managing children’s behaviour in the clinic</li> </ul>	<p><i>Self-efficacy / perceived behavioural control (TPB)</i>  <i>Self-efficacy / perceived behavioural control (TPB)</i>  <i>Anticipated affect</i>  <i>Anticipated affect / attitude towards waiting</i>  <i>Self-efficacy / perceived behavioural control (TPB)</i></p> <p><i>Self-efficacy / perceived behavioural control (TPB)</i></p>
<p><b>Theme 6. Responsibilities</b></p> <ul style="list-style-type: none"> <li>• Perceived parental responsibility to attend</li> <li>• Perceived impact of non-attendance on other families</li> <li>• Perceived impact of non-attendance on the healthcare professional</li> </ul>	<p><i>Personal/ moral norms</i>  <i>Moral norm / belief about outcome of non-attendance (TPB)</i>  <i>Moral norm / belief about outcome of non-attendance (TPB)</i></p>

CS-SRM: Leventhal’s Common-sense Self-Regulation Model; N&C: Horne & Weinman’s Necessity & Concerns framework; TPB: Ajzen’s Theory of Planned Behaviour

### Other variables

In addition to the cognitive variables necessary for explaining parents' beliefs about attending, other measures were needed for describing the characteristics of the sample and providing context for respondents' views. A small number of items assessing the ways in which participants interact with health services for their children were included as potentially useful sources of information to feedback to the hospital and General Paediatric service. For example, one item was designed to quantify the number of parents who requested referrals to the hospital service and the number for whom the referral was recommended by a GP or other healthcare professional, and a second item evaluated the types and number of strategies used by parents to remember appointments. The following descriptive and demographic variables were therefore included in the questionnaire.

#### **Demographic and child health variables:**

- Age of the child; sex of the child; child's health issue for which an upcoming General Paediatric appointment is scheduled; any other health issues; age of the parent; sex of the parent; number of children cared for by the parent; assistance with parenting (i.e. single parenting vs. joint parenting); parent's employment status; parent's level of education; parent's ethnicity; parent's religion

#### **Health service use variables:**

- Whether the upcoming appointment is scheduled in the next two weeks or not; whether the child's GP has been seen for this health issue; whether the General Paediatric service has already been seen for this health issue; urgent care services used for this health issue; whether the upcoming hospital appointment was requested by the parent or recommended by a healthcare professional; the source of referral (e.g. GP, doctor in the emergency department, other hospital service); strategies used by parents to remember the appointment.

Parental ethnicity and religion were both included and measured separately as it was felt that neither variable on its own could adequately reflect the underlying construct of interest, which encompasses the social and cultural behaviours and beliefs that can influence health service use. For example, Gatrad (1997) observed differences in attendance rates between Muslim British-Asian families and Hindu or Sikh British-Asian families, ostensibly due to Islamic 'religious holidays'. Thus, a blanket measure of ethnicity may mask important differences between these discrete cultural groups.



The temporal proximity of the reference behaviour (i.e. whether that appointment was in the next two weeks or not) was considered an important variable to include, as the relative importance of different cognitions were likely to alter as the appointment neared. For example, perceptions of the child's health and of the family's ability to attend the appointment may have become more salient as the date of the clinic visit approached.

#### ***6.2.1.2 Developing the questionnaire items***

Once the desired variables were established, existing instruments and measurement guidelines were reviewed in order to develop the questionnaire items to measure each variable. Questions were adapted from twelve such measures and guidelines. Table 14 shows the final list of 19 cognitive variable categories to be assessed by the questionnaire, the source from which the measurement items were adapted, and the specific questionnaire items measuring each variable.

Note that most of the variables were measured by more than one item. This is recommended practice to reduce idiosyncrasies in responses to particular questions and to improve the validity of the measurement procedure (DeVellis, 2003). Moreover this ensures that the different facets of a given construct are adequately represented (Sutton, 2005). For example, Conner & Sparks (2005, p.197) recommend that between four and six statements are used to measure attitudes as part of a Theory of Planned Behaviour model so that both experiential (e.g. pleasant vs. unpleasant) and instrumental (e.g. harmful vs. beneficial) aspects of attitude are included. Thus, questionnaire items 12a, b, c, and d were intended as a combined measure of attitude, as long as internal consistency among the items was confirmed using the Cronbach's alpha measure.

The exception to this approach was question 19 which measured perceptions of self-efficacy associated with performing various aspects of attendance behaviour, such as remembering the appointment, travelling to the clinic, and interacting with the doctor. Given the diverse nature of these actions, it was intended that the items measuring self-efficacy would be combined into several sub-measures, again depending on internal reliability.

The rating scales used in the questionnaire generally adhered to the format suggested by the guidelines or empirical research from which the items were adapted, including Likert scales (i.e. strongly agree to strongly disagree) and other similar five-point rating scales. The health service use and demographic items were self-developed, though some demographic questions were informed by those used in the most recent UK census (Office for National Statistics, 2013). A mixture of closed, one-choice questions (e.g. "Are you male or female?") and open questions were used for these measures. Finally, the wording of all questionnaire items were checked according to the guidance

provided by Fowler (2009, p.88) to maximise the reliability of participants' responses by improving poorly defined terms and amending incomplete questions.

### ***6.2.1.3 Presentation and pilot testing of the questionnaire***

Following development of the individual questionnaire items, the final instrument was constructed (see appendix 2.1). Questions were logically ordered according to 'themes' such that service use questions appeared together, as did cognitive items about attending appointments, cognitive items about the child's health, and finally, demographic questions. A table structure and colour-coding of items was used to facilitate navigation of the questionnaire. Logos of the university and hospital were included, and questionnaires were professionally printed on high quality paper to improve the perceived credibility of the study. The questionnaire was presented to participants as an A4 booklet to further improve ease of completion.

The final questionnaire booklet was pilot tested with six individuals who had experience of taking children to a hospital for outpatient appointments. These individuals were recruited through an email newsletter, which is delivered to academic and non-academic staff members at the University of Aston, and through word-of-mouth at the University of Birmingham. These pilot testers were asked to read and give feedback on a printed copy of the questionnaire as well as the study participant invitation letter and information sheet. In particular they were asked about the language, presentation, content and ease of completion of the form. They were also asked about how they would respond to receiving such a questionnaire by post.

Feedback given by the pilot testers was mainly positive. All respondents reported that they would be happy with receiving a survey by post and would be willing to complete the form. Positive comments were made about the style and presentation of the form. Minor changes made as a result of pilot testing included changing the question regarding parent's age from an open question to an age-bracket response format; presenting all rating scales in the same direction (i.e. negative to positive) to reduce completion error; and ordering the questions to appear in a roughly 'chronological' order according to one respondent, so that general beliefs about the appointments occurred prior to beliefs about what it would be like getting to the appointment and being in the clinic.

**Table 14. Cognitive variables to be measured and sources of questionnaire items**

	<b>Variable to be measured</b>	<b>Source of questionnaire item</b>	<b>Questionnaire item</b>
1.	Satisfaction with GP care	Ware & Hays (1988) <i>Methods for measuring patient satisfaction with specific medical encounters</i>	4a. How would you rate your child's visits to the GP for this health issue? 5a. In general, how would you rate the personal manner of your child's GP? (e.g. respect, friendliness) 5b. In general, how would you rate the medical competence of your child's GP? (e.g. knowledge, thoroughness)
2.	Satisfaction with General Paediatric care	Ware & Hays (1988) <i>Methods for measuring patient satisfaction with specific medical encounters</i>	7a. Overall, how would you rate your child's visits to the General Paediatric service? 7b. How would you rate the personal manner of the hospital doctor? (e.g. respect, friendliness) 7c. How would you rate the medical competence of the hospital doctor? (e.g. knowledge, thoroughness) 7d. How would you rate the length of time waiting in the waiting area to see the hospital doctor? 10. How would you rate the length of time waiting for the upcoming hospital appointment?
3.	Attitude towards attending the upcoming appointment	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	12. On a scale of 1 to 5, attending my child's hospital appointment would be: a. Worthless – Useful b. Unpleasant – Pleasant c. Inconvenient – Convenient d. Unimportant – Important
4.	Beliefs about necessity of the upcoming appointment	Horne et al. (1999) <i>Beliefs about medicines questionnaire</i>	13a. Attending my child's hospital appointment will make my child's health issue <i>better</i> 13b. Attending my child's hospital appointment will stop my child's health issue becoming <i>worse</i> 13c. My child's <i>current</i> health depends on attending the hospital appointment 13d. My child's <i>future</i> health depends on attending the hospital appointment

	Variable to be measured	Source of questionnaire item	Questionnaire item
5.	Beliefs about outcomes of the upcoming appointment	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	14. If I attend my child's hospital appointment: a. I will be given advice or support to manage the health issue b. My child will receive treatment for the health issue c. I will better understand my child's health issue d. It will make me feel reassured
6.	Concerns about attending the upcoming appointment	Horne et al. (1999) <i>Beliefs about medicines questionnaire</i>	15a. Having to go to the appointment worries me 15b. I worry that the doctor will prescribe a medicine or treatment I don't agree with 15c. I worry that the doctor will judge me for my child's health issue
7.	Anticipated affect while waiting in the waiting area for the upcoming appointment	Moan et al. (2005) <i>Predicting parents intentions not to smoke indoors in the presence of their children using an extended version of the Theory of Planned Behaviour</i>	16. While waiting in the waiting area for the appointment, how much do you think you would feel these emotions? a. Relaxed b. Anxious c. Frustrated
8.	Anticipated affect while with the doctor during the upcoming appointment	Moan et al. (2005) <i>Predicting parents intentions not to smoke indoors in the presence of their children using an extended version of the Theory of Planned Behaviour</i>	17. While you are with the doctor during the appointment, how much do you think you would feel these emotions? a. Relaxed b. Anxious c. Frustrated
9.	Perceived self-efficacy to attend the upcoming appointment	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	18a. I am confident that I could attend my child's hospital appointment
10.	Perceived control over attending the upcoming appointment	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	18b. I am completely in control of whether I go to the hospital appointment or not 18c. I feel that I had a choice about the time of the hospital appointment

	<b>Variable to be measured</b>	<b>Source of questionnaire item</b>	<b>Questionnaire item</b>
11.	Perceived self-efficacy to complete different necessary behaviours for the upcoming appointment  (preparing for the appointment, getting to the appointment, managing at the clinic, and interacting with the doctor)	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	19. How easy or difficult would you find each of these parts of attending the hospital appointment? a. Remembering the appointment b. Taking time away from other responsibilities c. Getting your child to go to the appointment d. Having the money to go to the appointment e. Travelling to the appointment f. Checking in at the reception desk g. Managing your child/children's behaviour h. Asking the doctor questions i. Telling the doctor your concerns j. Understanding what the doctor tells you
12.	Perceived social support for attending the upcoming appointment	Power et al. (1988) <i>The development of a measure of social support : The Significant Others (SOS) Scale</i>	20. How much do you feel you could get practical help from someone close to you to attend your child's hospital appointment if you needed it?
13.	Subjective norms about attending the upcoming appointment  Descriptive norm about attending the upcoming appointment	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	21a. I feel under social pressure to attend my child's hospital appointment 21b. My family and friends think I should attend my child's hospital appointment 21c. My child's GP (General Practitioner) thinks I should attend the hospital appointment 21d. Other parents like me would attend their child's hospital appointment
14.	Personal / moral norm about attending the upcoming appointment	Sparks & Guthrie (1998) <i>Self-Identity and the Theory of Planned Behavior: A Useful Addition or an Unhelpful Artifice?</i>	21e. Attending my child's hospital appointment would be the right thing to do 22e. I would not be meeting my responsibilities as a parent

	<b>Variable to be measured</b>	<b>Source of questionnaire item</b>	<b>Questionnaire item</b>
15.	Beliefs about outcomes of missing the upcoming appointment	Francis et al. (2004) <i>Constructing questionnaires based on the Theory of Planned Behaviour</i> Conner & Sparks (2005) <i>Theory of Planned Behaviour and Health Behaviour</i>	22a. I would have to wait a long time for another one 22b. I would feel guilty 22c. The doctor's time would be wasted 22d. It wouldn't be fair on other families
16.	Attitudes towards hospital doctors in general	Marteau et al. (1990) <i>Attitudes towards doctors and medicine: the preliminary development of a new scale</i>	24. This question is about your views on hospital doctors in general. a. If a child is sent to see a hospital doctor it must be important b. Hospital doctors know what's best for children c. I don't like hospital doctors d. No matter how long you have to wait to see a hospital doctor, it's worth it
17.	Perceived health status of the child	Stewart et al. (1988) <i>The MOS Short-Form General Health Survey: Reliability and Validity in a Patient Population</i>	25. Thinking about the health issue that the hospital appointment is for, in the past 4 weeks: a. How much physical pain due to the health issue has your child experienced? b. How much emotional upset because of the health issue has your child has experienced? 26. Thinking about the impact of this health issue on your child's daily life in the past 4 weeks, how have things been going for them? 29. In general, how would you rate your child's health?

	Variable to be measured	Source of questionnaire item	Questionnaire item
18.	<p>Illness representations of the child's health issue</p> <p>coherence/ understanding</p> <p>timeline (acute/chronic)</p> <p>timeline (cyclical)</p> <p>consequences</p> <p>personal control</p> <p>treatment control</p> <p>emotional representations</p>	<p>Moss-Morris et al. (2002)</p> <p><i>The Revised Illness Perception Questionnaire</i></p>	<p>27b. This health issue doesn't make any sense to me</p> <p>27l. I completely understand my child's health issue</p> <p>27h. The health issue will last a short time</p> <p>27k. I expect my child to have this health issue for a long time</p> <p>27c. There are cycles when the health issue gets better and worse</p> <p>27a. This health issue is a serious condition</p> <p>27e. The health issue does not have much effect on my child's life</p> <p>27g. I can affect whether the health issue gets better or worse</p> <p>27m. Nothing I do will have an effect on the health issue</p> <p>27d. There is nothing medically that can help the health issue</p> <p>27i. The health issue can be improved with treatment</p> <p>27f. My child having this health issue makes me feel anxious</p> <p>27j. This health issue does not worry me</p>
19.	<p>Attitude toward waiting time for the upcoming appointment</p>	<p>Ziarnowski et al. (2009)</p> <p><i>Present choices, future outcomes: Anticipated regret and HPV vaccination</i></p>	<p>27n. The hospital appointment waiting time is too long for this health issue</p>

## **6.2.2 Conducting the study**

### ***6.2.2.1 Ethical approval***

Ethical approval for this study was obtained from the Proportionate Review Sub-committee of the NRES Committee, Yorkshire & The Humber - Humber Bridge and the Life and Health Sciences Research Ethics Committee at Aston University. NHS Research and Development approval was also obtained from Birmingham Children's Hospital NHS Foundation Trust and Heart of England NHS Foundation Trust (see appendix 2.2 for evidence of approvals).

Participation was entirely voluntary and anonymous. No personal information was collected or accessed by the researcher for recruitment, and no highly sensitive topics were included in the questionnaire. Contact details for the researcher were provided for further information, and consent for anonymous data to be used in the research was explicitly indicated by return of a completed form. Participation burden was minimised through the use of reply-paid envelopes for returning the questionnaire, and respondents derived no personal benefit from taking part. However a small donation of one pound was offered to a children's charity of the respondent's choice on return of a completed form.

### ***6.2.2.2 Study design and setting***

This research was a cross-sectional study of parents' beliefs about attending children's General Paediatric outpatient appointments, administered through large-scale postal survey methods. The study was conducted at two hospitals in Birmingham, in the West Midlands region of the UK. Birmingham Children's Hospital was the main setting for the majority of the research conducted for this thesis. As previously mentioned, BCH is a specialist hospital providing tertiary paediatric services at regional and national levels, but also delivering secondary care to children and young people in Birmingham. A second research site was desirable for two reasons. First, given that there are relatively few such specialist paediatric centres in the UK providing secondary care services for children, it was apparent that the majority of families referred for General Paediatric care would receive services at local District General Hospitals (DGHs). It was therefore useful to also consider the beliefs of parents attending appointments in these settings. Second, the inclusion of another hospital site increased the likelihood of obtaining a sufficient sample size within a relatively short data collection period. Heartlands Hospital (HH), administered by Heart of England NHS Foundation Trust, was consequently selected as a complementary additional research site. This hospital is a DGH providing secondary care services to children and adults in the East of Birmingham.



### **6.2.2.3 Sampling and selection**

Potential participants were identified by hospital administrators via clinic records of future appointments. All parents of children booked to attend a General Paediatric appointment in an upcoming two month period were selected for invitation to the study. This included those scheduled to attend first and follow-up appointments, but excluded appointments with specialist nurses rather than consultants, weekend clinics, and off-site outreach clinics. Parents' cognitions about attending these types of appointments were likely to differ significantly from those at standard clinics due to issues around accessibility, attitudes towards healthcare personnel, and beliefs about appropriate locations for care, and so these families were not included in this initial exploratory analysis.

Both hospitals estimated that approximately 1000 appointments could be expected to be scheduled in an upcoming two month period. Two months were selected as an appropriate amount of time ahead of an appointment in which parents could be questioned about attending. Appointments scheduled further in the future may have been difficult for participants to consider as circumstances and the child's condition would be likely to change considerably before the time of the visit, and the appointment may not be salient in the parents' thoughts this far in advance. For the same reasons, cognitions measured too far ahead of the anticipated appointment would be unlikely to usefully predict attendance behaviour and so would not be helpful as a basis for developing theory and measures related to attendance. Consequently families invited to participate were limited to those scheduled to attend within the selected upcoming two month period. There were no other inclusion criteria for participation in the study.

### **6.2.2.4 Sample size**

Recent literature on sample sizes for exploratory factor analyses suggests that adequate numbers depend on the characteristics of the data collected (Costello & Osborne, 2009), including common variance between variables and resulting factor loadings (Field, 2013, p.684). However, as this was the first time that these cognitions were measured in this type of population, the strength and nature of the data could not be estimated beforehand. As such, a larger sample size was desirable. Some authors recommend a sample size of at least 300 participants (Tabachnick & Fidell, 2012, p.613) while other suggest that a ratio of at least five participants to every variable included in the analysis is required (Gorsuch, 1974, cited in Ford et al., 1986, p.297).

The questionnaire measured 75 discrete items for inclusion in the factor analysis, representing 28 distinct variables after splitting the items assessed under questions 19 and 27 into their constituent components. With the recommended ratio of five cases per variable, this would necessitate a

minimum sample of 140 participants. However, given the possibility of inadequate reliability between items resulting in entering measures into the analysis individually, a sample of 250 parents was desirable to provide sufficient power for up to 50 final variables.

As both hospitals estimated that 1000 families would be scheduled to attend appointments in the specified two-month period, a questionnaire response rate of 12.5% was necessary. Survey response rates are difficult to estimate as they are influenced by diverse factors such as length of the document, level of interest to the recipient, use of incentives and stamped return envelopes, and origin of the questionnaire (e.g. university or commercial organisation) (Edwards et al., 2002). A recent population survey of parents of young children in Sweden reported a response rate of 28% when questionnaires were sent directly with no prior or subsequent contact (Stenhammar et al., 2011). Therefore an expected rate of 12.5% returns seemed reasonable.

#### **6.2.2.5 Recruitment and data collection**

All parents and caregivers of children with General Paediatric appointments scheduled in the two month period from the beginning of recruitment were invited to participate. The selected appointment periods at each site were October to December 2013 for BCH, and November 2013 to January 2014 for Heartlands Hospital. Parents were sent an envelope containing an invitation letter addressed to them personally, which contained information about the research on the reverse, a copy of the questionnaire form, an instruction and 'further' comment' sheet, and a reply-paid envelope (see appendix 2.3 for copies of these participant documents). The letter also included directions to an online version of the form and drew attention to the offer of a £1 donation to a children's charity of the participant's choice dependent on completion and return of the questionnaire.

The invitation packs were posted ten days prior to the first scheduled appointment in the invited cohort so as to permit sufficient time for completing and returning the form before these appointments. The questionnaire was designed to measure beliefs about an *upcoming* scheduled appointment so participants were instructed to fill in the form before attending the clinic. They were also informed that returning a completed questionnaire would indicate agreement to their anonymous responses being included in the data analysis.

Returned questionnaires were delivered via the reply-paid envelopes to an address at Aston University. Responses from participants from each site were identified by the particular NHS logo included on the different forms. Two different online versions of the questionnaire were created to collect data separately for each sub-group.

#### **6.2.2.6 Data analysis**

Only one response per research site was obtained via the online versions of the questionnaire. There were some issues with transferring the data from the online database to the main data set so these two cases were retained for later inclusion in subsequent tests, but were not included in the present analysis. The methods described in the remainder of this section therefore apply only to responses received by post. Data from the returned postal questionnaires were entered by hand into an electronic database.

Descriptive statistics were carried out to illustrate the characteristics of the final sample, including obtaining means and standard deviations for continuous variables (e.g. child age) and frequencies and percentages for categorical variables (e.g. participant's employment status). The distribution within the sample of demographic and health service variables, such as source of referral and whether the appointment was new or follow-up, were checked for bias against the distribution of these characteristics in the invited population using demographic data sets provided by both hospitals and Pearson's chi-square tests. A one sample t-test against the population mean was conducted to examine differences in child age, which was the only non-categorical variable. Similarly, differences in distributions of sample characteristics were compared between BCH and Heartlands participants using chi-square tests and an independent samples t-test for child age.

#### Beliefs about children's health issues

Prior to conducting the main statistical analyses it was decided to investigate cognitions related to children's health issues (i.e. items 25a to 29, except 27n regarding waiting time) separately from the other cognitive measures. Although findings of the qualitative interview study clearly indicated that beliefs about a child's health condition are extremely important for determining parental views about the importance of attending appointments, these beliefs were thought to be distinct from beliefs about the appointments themselves. An examination of the underlying belief structure would therefore reflect a split between these two belief types – those regarding appointments, and those regarding the child's illness. Although this might be somewhat useful, the primary aim of the factor analysis was to investigate the structure underlying beliefs about attending appointments. This would be a new and worthwhile contribution to existing knowledge. However, findings regarding the underlying structure of parents' beliefs about children's illnesses would merely contribute to the literature on illness perceptions and Leventhal's Common-Sense Self-Regulation Model (Leventhal et al., 2003) which was not the purpose of this study. Consequently the cognitive items regarding children's health issues were examined using descriptive statistics only, and were not included in the

factor analysis. It was hoped that this would facilitate the production of a clearer and more coherent factor structure related to beliefs about appointments.

Beliefs about children’s health issues were measured using 17 items. Five-point rating scales were used except for questions 25a and 25b regarding perceived amount of pain and emotional upset, which used a four-point rating scale from 0 to 3 to align with the scale descriptors, ‘none’, ‘a mild amount’, ‘a moderate amount’ and ‘a severe amount’. For the illness perception measures (items 27a to 27m) two items were used per variable, taken from the Revised Illness Perception Questionnaire (IPQ-R, Moss-Morris et al., 2002). One item was phrased positively, the other negatively. Perceived consequences of the illness were measured by items 27a and 27e; coherence by 27b and 27l; perceived timeline (cyclical) by 27c; perceived treatment control by 27d and 27i; emotional representations by 27f and 27j; perceived personal control by 27g and 27m; and perceived timeline (acute/chronic) by 27h and 27k.

Beliefs about attending children’s appointments

Descriptive statistics and histograms were checked for each cognitive questionnaire item related to attending appointments, to assess whether distributions were close to normal and whether there was sufficient variance within each item to be reasonably included in the factor analysis. Items with mean scores at either extreme of the response scale (<1.5 or >4.5 on a scale from 1.00 to 5.00) and small standard deviations (less than 1), and measures of skew substantially greater than 1 (or substantially smaller than -1) were not included in reliability analyses or in the factor analysis. This resulted in the removal of 7 out of 58 cognitive variables. These 7 items are presented in table 15, with means, standard deviations, and measures of skew to justify their exclusion.

**Table 15. Items removed due to extreme mean scores and skew**

Questionnaire item	Mean score	Standard deviation	Skewness
12a. Attending would be useful	4.77	.61	-3.10
12d. Attending would be important	4.70	.89	-3.32
18a. Confident I could attend	4.65	.81	-2.57
19f. Difficult to check in at reception	4.61	.74	-2.43
19h. Difficult to ask doctor questions	4.50	.78	-1.68
21e. Attending would be right thing to do	4.77	.72	-3.82
22e. Not meeting parent responsibility	4.58	.97	-2.73

*Mean scores <1.5 or >4.5 considered ‘extreme’; skew values <-1 or >1 considered unacceptably skewed*

Items purportedly measuring the same variable were tested for internal reliability using tests of Cronbach's alpha. Values of .7 or greater were accepted as indicating good reliability, in accordance with the recommendations of Giles (2002, p.115) and Field (2013, p.709). Following further guidance by Field (2013), correlations between each item and the total score were also checked to ensure sufficient correlation (greater than .3) and values of 'Cronbach's alpha if the item were deleted' were reviewed. If the Cronbach's alpha value would be greater if a particular item was not included, then the item was removed and entered into the analysis individually. Items with sufficient internal reliability were then combined by taking participants' mean responses and generating a composite variable for entry into the factor analysis. This led to the creation of 13 composite variables which are shown in table 16 with their Cronbach's alpha values. The remaining 18 items were entered into the factor analysis individually because of low internal reliability with other items, or because the items to which they related had been removed due to extreme mean scores. A total of 31 variables were therefore entered into the exploratory factor analysis.

An inferential method, the maximum-likelihood method, was selected since generalizing the findings of the study was desirable. It was reasonable to assume that the factors would not be independent of one-another and so oblique rotation (direct oblimin) was applied. Some items had relatively high proportions of missing values, with the greatest being 19.67% for items 7a and 7d. However, excluding cases with missing data could result in insufficient sample sizes for the associated variables. De Vet et al. (2005) proposed that for rates of <25% missing data, imputation of mean values was an acceptable method for managing item non-response. Therefore to retain an adequate sample missing values were replaced by mean scores.

The Kaiser-Meyer-Olkin measure verified that sampling was adequate for the analysis as a whole, KMO = .767 (a 'middling' or acceptable value according to Hutcheson & Sofroniou, 1999). However, examination of the anti-image correlation matrix (displaying the KMO value for individual variables) showed that 8 items had values less than .5, indicating inadequate sampling for these variables.

These variables were removed one by one, starting with the item with the smallest KMO value, and the analysis was re-run after every step until all values in the diagonal of the anti-image matrix were greater than .5, signifying an adequate sample for every variable. This process resulted in the removal of four variables: beliefs about treatment outcomes of attending the appointment (composite item of measures 14a and 14b); satisfaction with General Paediatric care (composite item of measures 7a, 7b and 7c); perceived difficulty of interacting with the doctor (composite item of measures 19i and 19j); and beliefs about moral outcomes of missing the appointment (composite

item of measures 22c and 22d). The overall Kaiser-Meyer-Olkin remained acceptable at KMO = .732, indicating sampling adequacy for the factor analysis.

**Table 16. Internal reliability of composite variables**

Composite variable	Constituent items	Cronbach's alpha
Satisfaction with GP care	4a. Rate GP visits 5a. Rate GP manner 5b. Rate GP competence	.886
Satisfaction with General Paediatric care	7a. Rate General Paediatric visits 7b. Rate General Paediatrician manner 7c. Rate General Paediatrician competence	.912
Attitude toward waiting time	10. Rate waiting time 27n. Wait is too long for this health issue	.721
Experiential attitude toward attending the appointment	12b. Will be pleasant 12c. Will be convenient	.794
Perceived necessity of the appointment	13a. Will make issue better 13b. Will prevent issue becoming worse 13c. Current health depends on attending 13d. Future health depends on attending	.884
Beliefs about treatment outcomes of attending the appointment	14a. Will be given advice or support to manage 14b. Child will receive treatment	.712
Beliefs about personal outcomes of attending the appointment	14c. Will better understand health issue 14d. Will feel reassured	.914
Specific concerns about attending	15b. Worry about prescribed medicines 15c. Worry doctor will judge me	.758
Anticipated affect while with the doctor	17b. Will feel anxious 17c. Will feel frustrated	.755
Perceived difficulty of getting to appointment	19b. Taking time away from other things 19c. Getting child to go 19d. Having money to go 19e. Travelling to the appointment	.744
Perceived difficulty of interacting with the doctor	19i. Telling doctor my concerns 19j. Understanding what doctor tells me	.794
Subjective norm	21b. Family and friends think I should attend 21c. GP thinks I should attend 21d. Other parents like me would attend	.788
Beliefs about moral outcomes of missing the appointment	22c. Doctor's time would be wasted 22d. Wouldn't be fair on other families	.875

### 6.3 RESULTS

A total of 1860 invitation letters and questionnaires were posted. From BCH 998 letters were sent, and a further 862 from Heartlands Hospital. This constituted all families scheduled to attend General Paediatric outpatient appointments in an upcoming two month period. A response rate of 13.06%, or 243 replies, was achieved. However, the response rate was much higher for the BCH group than the HH group, with 192 (19.24%) and 51 (5.92%) replies respectively.

As mentioned in the preceding section, two responses received via online forms (one from the BCH group and one from the HH group) could not be integrated into the main data set prior to analysis and were retained for future testing. Two other responses from parents in the BCH group were excluded from the analyses. One noted under question 3 (“What health issue is the hospital appointment for?”) that they weren’t sure which condition to describe as they were not previously aware that they had an appointment scheduled. As the questionnaire was designed to measure cognitions about a specific, known appointment, this case was not suitable for inclusion. A second participant had returned two forms in one envelope, one for each of her sons who both had allergies to nuts and eggs. The responses given on the cognitive measures were exactly the same on each form, except for one scale point difference on one item. One of the records for this participant was randomly selected, and the other was excluded from the analysis. This left a final total sample of 239 cases, or 12.85% of the invited group.

### **6.3.1 Sample characteristics**

#### Demographic information

The sample comprised 202 women (84.5%) and 33 men (13.8%), with 4 cases where this data was not reported (1.7%). The majority of the sample was between the ages of 25 and 44 (n=170, 71.1%), though 10.5% (n=25) were aged 24 years or younger, and 17.5% (n=42) were aged 44 years or older. One-hundred-and-twenty-seven participants were employed or self-employed (53.1%), 3 were in full time education (1.3%), 12 (5%) were temporarily away from work (e.g. due to ill health or maternity leave), and 93 (38.9%) were not currently doing any paid work. In terms of education, most participants were educated to at least degree level (n=141, 59%). A further 12.1% (n=29) had qualifications in addition to secondary schooling, 22.2% (n=53) had completed secondary school education, and 3.3% (n=8) had received only primary level teaching.

Nine ethnicity classifications were identified in the sample, and five religious classifications. The full distribution of these groupings is provided in table 17, though as might be expected for this region the main classifications were ‘White British’ (n=138, 57.7%) and ‘South Asian/British-South Asian’ (n=59, 24.7%) for ethnicity, and Christian (n=96, 40.2%) and Muslim (n=63, 26.4%) for religious group.

The number of children cared for by participants ranged from 1 to 6, with 1, 2 or 3 children being most common (n=196, 84.1%). Thirty-five participants (14.6%) cared for four or more children. Forty-nine (20.5%) respondents indicated that they had no help with child care from another adult, such as a partner or other parent of the children. Finally, 108 (45.2%) participants noted that the child for

**Table 17. Sample characteristics – demographic variables**

Demographic variable		Total sample (n=239)	BCH sample (n= 189)	HH sample (n=50)	Testing for differences between BCH and HH
Age	24 or younger	25 (10.5%)	18 (9.5%)	7 (14.0%)	$\chi^2(4) = 1.94, p = .747$
	25-34	75 (31.4%)	58 (30.7%)	17 (34.0%)	
	35-44	95 (39.7%)	77 (40.7%)	18 (36.0%)	
	44-54	40 (16.7%)	33 (17.5%)	7 (14.0%)	
	55 or older	2 (0.8%)	2 (1.1%)	0 (0.0%)	
	Not reported	2 (0.8%)	1 (0.5%)	1 (2.0%)	
Sex	Male	33 (13.8%)	27 (14.3%)	6 (12.0%)	$\chi^2(1) = .119, p = .730$
	Female	202 (84.5%)	160 (84.7%)	42(84.0%)	
	Not reported	4 (1.7%)	2 (1.1%)	2 (4.0%)	
Employment status	Employed or self-employed	127 (53.1%)	107 (56.6%)	20 (40.0%)	$\chi^2(3) = 8.76, p = .033 *$
	Temporarily away from work	12 (5.0%)	11 (5.8%)	1 (2.0%)	
	In full time education	3 (1.3%)	3 (1.6%)	0 (0.0%)	
	Not doing any paid work	93 (38.9%)	65 (44.4%)	28 (56.0%)	
	Not reported	4 (1.7%)	3 (1.6%)	1 (2.0%)	
Level of education	University	141 (59.0%)	123 (65.1%)	18 (36.0%)	$\chi^2(3) = 25.98, p <.001 **$
	Other qualifications	29 (12.1%)	24 (12.7%)	5 (10.0%)	
	Secondary	53 (22.2%)	35 (18.5%)	18 (36.0%)	
	Primary	8 (3.3%)	2 (1.1%)	6 (12.0%)	
	Not reported	8 (3.3%)	5 (2.6%)	3 (6.0%)	
Ethnicity	White British	138 (57.7%)	113 (59.8%)	25 (50.0%)	$\chi^2(7) = 9.24, p = .236$
	South Asian	59 (24.7%)	42 (22.2%)	17 (34.0%)	
	Black African	9 (3.8%)	7 (3.7%)	2 (4.0%)	
	Mixed	7 (2.9%)	5 (2.6%)	2 (4.0%)	
	White Other	5 (2.1%)	5 (2.6%)	0 (0.0%)	
	Other	3 (1.3%)	3 (1.6%)	0 (0.0%)	
	Black British	1 (0.4%)	0 (0.0%)	1 (2.0%)	
	Black Caribbean	1 (0.4%)	1 (0.5%)	0 (0.0%)	
	Not reported	16 (6.7%)	13 (6.9%)	3 (6.0%)	



**Table 17. (continued)**

Demographic variable	Total sample (n=239)	BCH sample (n= 189)	HH sample (n=50)	Testing for differences between BCH and HH
Religion				$\chi^2(4) = 3.00, p = .559$
Christian	96 (40.2%)	80 (42.3%)	16 (32.0%)	
Muslim	63 (26.4%)	46 (24.3%)	17 (34.0%)	
None	40 (16.7%)	32 (16.9%)	8 (16.05)	
Sikh	7 (2.9%)	5 (2.6%)	2 (4.0%)	
Pagan	1 (0.4%)	1 (0.5%)	0 (0.0%)	
Not reported	32 (13.4%)	25 (13.2%)	7 (14.0%)	
Number of children for whom providing care				$\chi^2(5) = 6.46, p = .374$
1	48 (20.1%)	40 (21.2%)	8 (16.0%)	
2	97 (40.6%)	78 (41.3%)	19 (38.0%)	
3	51 (21.3%)	38 (20.1%)	13 (26.0%)	
4	24 (10.0%)	19 (10.1%)	5 (10.0%)	
5	5 (2.1%)	2 (1.1%)	3 (6.0%)	
6	6 (2.5%)	5 (2.6%)	1 (2.0%)	
Not reported	8 (3.3%)	7 (3.7%)	1 (2.0%)	
Assistance with child care from another adult				$\chi^2(1) = .07, p = .790$
Yes	174 (72.8%)	138 (73.0%)	36 (72.0%)	
No	49 (20.5%)	38 (20.1%)	11 (22.0%)	
Not reported	16 (6.7%)	13 (6.9%)	3 (6.0%)	
Child sex				$\chi^2(1) = 7.889, p = .005 **$
Male	125 (52.3%)	90 (47.6%)	35 (70.0%)	
Female	108 (45.2%)	94 (49.7%)	14 (28.0%)	
Not reported	6 (2.5%)	5 (2.6%)	1 (2.0%)	
Child age	Mean 7.18 (SD 4.77)	Mean 7.13 (S.D. 4.73)	Mean 7.36 (S.D. 4.94)	$t(231) = -.30, p = .764$

*\*significant at p<.05 level*

*\*\*significant at p<.01 level*

whom the upcoming appointment was scheduled was female, and 125 (52.3%) of the children were male. The children ranged in age from 9 weeks to 16 years old, though any age less than 1 was recorded as 0 for the purposes of analysis. The average age of the children was 7.18 years old (S.D. 4.77), though a histogram of the distribution of this variable showed that there were noticeable peaks at 1, 3 and 12 years of age.

The samples from BCH and HH were equivalent in terms of parent age, sex, ethnicity, religion, number of children cared for, child care assistance, and child age, as confirmed by chi-square analyses and an independent t-test (see table 17). However, the two groups were significantly different in terms of level of education ( $\chi^2(3) = 25.98, p < .001$ ), employment status ( $\chi^2(3) = 8.76, p = .033$ ), and child sex ( $\chi^2(1) = 7.889, p = .005$ ). The BCH sample had a greater proportion of participants reporting university level education (65.1% vs 36.0% at HH) and a greater percentage who were employed or self-employed (56.6% vs 40%). The distribution of male and female children in the BCH sample was roughly equal (47.6% male, 49.7% female), however there was a much higher proportion of male children recorded within the HH sample (70% male, 28% female).

Differences were also investigated between the sample groups and the populations from which they were drawn. Demographic data sets from the clinic records at each hospital were obtained. These data sets contained information about all families scheduled to attend General Paediatric appointments in the same time period as the study (i.e. all of the families invited to participate). Data regarding child sex, child ethnicity, and child age were included. Chi-square analyses were conducted for the two categorical variables, and a one-sample t-test was carried out for the child age variable to compare the sample mean to the population mean.

The HH sample did not differ from the population on any of the variables. BCH did not differ from the population regarding child sex ( $\chi^2(1) = .939, p = .333$ ), but there were significant differences in terms of ethnicity ( $\chi^2(6) = 37.53, p < .001$ ) and child age ( $t(182) = 2.40, p = .017$ ). The BCH sample had a much higher proportion of White British participants (59.8%) compared to the population (39.5%), and corresponding reductions in the proportion of all other ethnicity groupings. It should be noted that the population data refers to child ethnicity, whereas the questionnaire sample reported parental ethnicity, so some differences might be expected. However, a 20% difference in proportion suggests some degree of bias in terms of the ethnicity category. The mean age of children in the questionnaire sample (7.13, S.D. 4.73) was also significantly higher than patients in the population records (6.29, S.D. 4.69).

### Health service use information

The sample was roughly evenly split between participants whose children had an appointment scheduled in the next two weeks (n=102, 42.7%) and those whose appointments were later in the two month period (n=110, 46.0%). The majority (n=202, 84.5%) had previously seen a GP for their child's health issue, and the children of 191 participants (79.95%) had had prior contact with the General Paediatric service regarding this health issue. Furthermore, 54% of respondents (n=129) reported having utilised an urgent care service for this health issue, such as an emergency department, walk-in centre, or GP out-of-hours service. Regarding source of referral, 133 participants indicated that a GP had referred them to the General Paediatric service (55.6%), 34 had been referred via an emergency department (14.2%), and 34 by other hospital services (14.2%). The remaining 25 respondents (10.5%) reported more than one source of referral or other professionals. Just over one third of participants had requested the referral (n=89, 37.2%), but 59.8% (n=143) indicated that the referral had been suggested by a healthcare professional. There were no significant differences between responses from BCH participants and HH participants on any health service use variables, confirmed by chi-square tests (see table 18). Neither questionnaire sample significantly differed from the population from which they were drawn in terms of number of new versus follow-up appointments (whether seen previously by the General Paediatric service). However, the BCH sample did differ from the population regarding source of referral, or who arranged the appointment ( $\chi^2(5)=126.70$ ,  $p<.001$ ). This data was not available for comparison in the HH population data set.

### Reported health issues

Participants were asked to complete an open question to describe the health issue for which the upcoming appointment was scheduled. Responses were given in terms of problems and symptoms, bodily systems, named diseases and disorders, and purpose of the appointment (e.g. check up, investigations). Issues ranged from behavioural problems, to injuries, to chronic health conditions, and forty different categories of 'health issue' were identified. 11.3% of participants reported that their children had multiple health issues. The distribution of issues within the sample is presented in table 19.

#### **6.3.2 Perceptions of children's health issues**

Illness perception variable pairs were tested for internal reliability by reverse scoring one of the items to make scores equivalent, and conducting a Cronbach's alpha test. This process highlighted problems with the internal reliability of variable pairs, as all couplings had low Cronbach's alpha

**Table 18. Sample characteristics - health service use variables**

Health service use variable	Total sample (n=239)	BCH sample (n=189)	HH sample (n=50)	Testing for differences between BCH and HH
Appointment in next two weeks				
Yes	102 (42.7%)	79 (41.8%)	23 (46.0%)	$\chi^2(1) = .39, p = .535$
No	110 (46.0%)	89 (47.1%)	21 (42.0%)	
Not reported	27 (11.3%)	21 (11.1%)	6 (12.0%)	
Previously seen GP				
Yes	202 (84.5%)	163 (86.2%)	39 (78.0%)	$\chi^2(1) = 2.38, p = .123$
No	32 (13.4%)	22 (11.6%)	10 (20.0%)	
Not reported	5 (2.1%)	4 (2.1%)	1 (2.0%)	
Previously seen General Paediatrics				
Yes	191 (79.9%)	150 (79.4%)	41 (82.0%)	$\chi^2(1) = .08, p = .777$
No	46 (19.2%)	37 (19.6%)	9 (18.0%)	
Not reported	2 (0.8%)	2 (1.1%)	0 (0.0%)	
Previously used urgent care services				
Yes	129 (54.0%)	107 (56.6%)	22 (44.0%)	$\chi^2(1) = 3.63, p = .057$
No	102 (42.7%)	74 (39.2%)	28 (56.0%)	
Not reported	8 (3.3%)	8 (4.2%)	0 (0.0%)	
Source of referral				
GP	133 (55.6%)	108 (57.1%)	25 (50.0%)	$\chi^2(5) = 7.30, p = .199$
Emergency department	34 (14.2%)	31 (16.4%)	3 (6.0%)	
Other hospital service	34 (14.2%)	25 (13.2%)	9 (18.0%)	
School	9 (3.8%)	7 (3.7%)	2 (4.0%)	
More than one referrer	7 (2.9%)	6 (3.2%)	1 (2.0%)	
Other	9 (3.8%)	5 (2.6%)	4 (8.0%)	
Not reported	13 (5.4%)	7 (3.7%)	6 (12.0%)	
Requested appointment				
Yes	89 (37.2%)	70 (37.0%)	19 (38.0%)	$\chi^2(1) = .004, p = .953$
No	143 (59.8%)	112 (59.3%)	31 (62.0%)	
Not reported	7 (2.9%)	7 (3.7%)	0 (0.0%)	

values of approximately .3 to .4 indicating poor reliability. Examination of the distribution of scores for these variables using histograms showed that for some items there was noticeable participant avoidance of scores 2 and 4 on the five point scale. Reliability problems could also have been influenced by respondent fatigue as there were many items in this section near the end of the questionnaire; difficulty completing negatively phrased items on a scale of agreement; perceived repetition of items; lack of specificity regarding the health condition; and non-random dispersal of positive and negative statements across question 27. Table 20 shows the mean scores and standard deviations for each measure of beliefs about children's health issues with positively phrased statements reverse scored, as recommended by Moss-Morris et al. (2002).

**Table 19. Distribution of children's health issues**

<b>Health issue for which the appointment is scheduled</b>	<b>Number</b>	<b>Percentage</b>
Multiple conditions	27	11.30%
Allergies and allergy testing	21	8.79%
Epilepsy and seizures	16	6.69%
Asthma	11	4.60%
ADHD	10	4.18%
Problems with bowels and toileting	9	3.77%
Kidney problems	9	
Respiratory problems (not including asthma)	8	3.35%
Investigations and diagnoses	7	2.93%
Autistic spectrum disorders	6	2.51%
Stomach problems	6	
Physical problems (e.g. missing fingers, bowed legs)	5	2.09%
Problems with walking	5	
Behavioural problems	4	1.67%
Delayed development	4	
Dietary issues (e.g. coeliac disease, lactose intolerance)	4	
Heart problems	4	
Injuries	4	
Migraines and back pain	4	
Problems with growth	4	
Unclear or unspecified	4	
Urinary problems	4	
Brain problems (e.g. injury, water on the brain)	3	1.26%
Fainting and blackouts	3	
Muscular problems	3	
Problems with immune system (e.g. lymph nodes)	3	
Problems with thyroid	3	
Problems with body weight	3	
Check-ups after meningitis	2	0.84%
Enuresis	2	
Hearing problems	2	
Problems with puberty (e.g. early onset, 'anomalies')	2	
Addison's disease	1	0.42%
Cerebral Palsy	1	
Chromosomal disorder	1	
Chronic fatigue syndrome	1	
Lethargy	1	
Mental health issues	1	
Problems with genitals	1	
Problems with tonsils	1	
Vertigo	1	
Not answered	28	11.72%
<b>Total</b>	<b>239</b>	<b>100%</b>

**Table 20. Perceptions of children's health issues - means and standard deviations**

Variable	Number of valid cases	Mean	Standard deviation
27j. "The health issue does not worry me" (R)	234	4.20	1.14
27h. "The health issue will last a short time" (R)	226	4.01	1.21
27e. "Health issue does not have much effect on child's life" (R)	230	3.72	1.31
27k. "I expect child to have the issue a long time"	229	3.67	1.39
27a. "This health issue is a serious condition"	232	3.56	1.28
27f. "The health issue makes me feel anxious"	231	3.52	1.32
27c. "There are cycles when it gets better and worse"	228	3.19	1.52
27g. "I can affect whether it gets better or worse" (R)	230	3.08	1.48
27m. "Nothing I do will have an effect on the health issue"	229	2.69	1.27
27i. "The health issue can be improved with treatment" (R)	227	2.63	1.39
26. Perceived impact on child's daily life (doing badly – well) (R)	227	2.46	1.19
27l. "I completely understand the health issue" (R)	229	2.41	1.26
29. General rating of child health (poor – excellent) (R)	232	2.34	1.06
27d. "Nothing medically can help the health issue"	227	2.21	1.27
27b. "The health issue doesn't make sense to me"	232	2.14	1.32
25b. Perceived emotional upset <sup>a</sup>	236	1.35	1.06
25a. Perceived physical pain <sup>a</sup>	234	0.92	0.98

<sup>a</sup> Measured on a four-point scale from 0 to 3, or 'none' to 'a severe amount'

(R) Reverse scored

### 6.3.3 Beliefs about attending appointments

The two items that measured intention to attend the upcoming appointment were very negatively skewed, showing extreme positive mean scores for intention to attend. The mean score for the statement "I want to attend the appointment" (11a) was 4.85 (SD = .59, skew = -4.81), and the mean score for the statement "I intend to attend the appointment" (11b) was 4.78 (SD = .74, skew = -3.94). These items were not included in the factor analysis and are unlikely to be useful in secondary analyses of the data set given their lack extreme scores and lack of variance.

#### Results of the exploratory factor analysis

The desired 12.5% questionnaire response rate was exceeded, and a participant-to-variable ratio of 1:8.85 was achieved with a final sample of 239 cases and 27 variables. The exploratory factor analysis was therefore sufficiently powered, which was confirmed by the acceptable Kaiser-Meyer-Olkin statistic (KMO=.732). The initial analysis found eight factors with eigenvalues over 1, the criterion advocated by Kaiser (1960) for retaining factors. These factors in combination explained 43.14% of

the variance. However, Field (2013) notes that the Kaiser criterion is only accurate when there are less than 30 variables and communalities after extraction are greater than .7, or when sample size is greater than 250 and average communality is greater than or equal to .6. Neither of these criteria were met, meaning the number of factors to retain may have been over-estimated. The number of factors to extract was instead determined by examining the scree plot, which is a reliable method for factor selection in samples of more than 200 participants (Stevens, 2002). The scree plot had an unambiguous point of inflexion at the third factor, indicating that a two factor solution would be most appropriate (see figure 4). The analysis was run a final time to extract two rotated factors, which explained 22.92% of the variance.

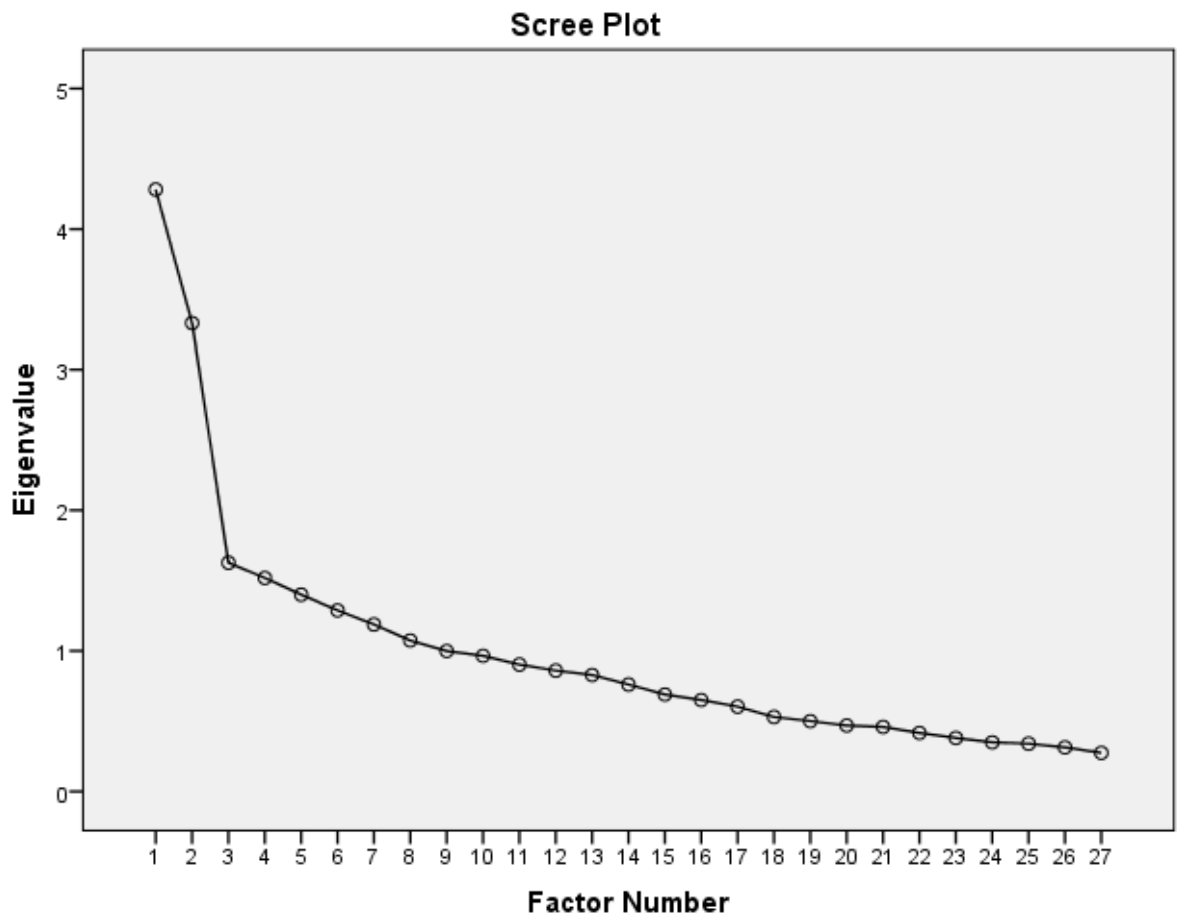


Figure 4. Scree plot for justifying factor extraction

Based on recommendations by Stevens (2002) regarding assessment of the substantive importance of variables to factors, factor loadings with an absolute value of greater than .4 were interpreted and used for factor labelling. By this criterion fourteen items sufficiently loaded onto the two factors and

no items were cross-loading, but 13 items did not load highly on either factor. Assessment of the remaining items suggested that a third factor could be present, related to perceived control over attending (e.g. perceived choice of appointment time, perceived practical help, self-efficacy to remember the appointment). A three factor solution was checked, but the resultant model did not incorporate any additional items and did not indicate an interpretation of the data that improved upon the two factor solution. The two factor solution indicated by examination of the scree plot was therefore retained. This is presented in table 21 with loadings of variables on factors, eigenvalues and the proportion of variance extracted by each factor reported.

**Table 21. Factor loadings for beliefs about attending appointments (pattern matrix)**

	Factor 1	Factor 2
Perceived necessity of the appointment (e.g. will make health issue better)	.645	
Beliefs about personal outcomes of attending the appointment (e.g. feel reassured)	.622	
'Hospital doctors know what's best for children'	.618	
'No matter how long you have to wait to see a hospital doctor, it's worth it'	.559	
'If a child is sent to see a hospital doctor it must be important'	.500	
Experiential attitude toward attending the appointment (e.g. unpleasant – pleasant)	.466	
Perceived difficulty of getting to appointment (e.g. travel, cost)	.415	-.315
Subjective norm (e.g. family and friends think I should attend the appointment)	.390	
'Rate the length of time waiting in the waiting area to see the hospital doctor'	.378	
'If I did not attend my child's hospital appointment, I would feel guilty'	.337	
Attitude toward waiting time (e.g. poor – excellent)	.315	
'I feel that I had a choice about the time of the hospital appointment'	.315	
Satisfaction with GP care (e.g. manner, competence)		
'I am completely in control of whether I go to the hospital appointment or not'		
'How easy or difficult would you find remembering the appointment?'		
'How much do you feel you could get practical help... to attend the appointment?'		
'While waiting in the waiting area, how much would you feel anxious?'		.665
Anticipated affect while with the doctor (e.g. anxious, frustrated)		.664
'While waiting in the waiting area, how much would you feel frustrated?'		.656
'Having to go to the appointment worries me'		.553
Specific concerns about attending (e.g. being judged by the doctor)		.517
'I don't like hospital doctors'		.444
'While waiting in the waiting area, how much would you feel relaxed?'		-.425
'While you are with the doctor, how much would you feel relaxed?'		-.362
'How easy or difficult would you find managing your child's behaviour?'		
'If I did not attend the appointment I would have to wait a long time for another'		
'I feel under social pressure to attend my child's hospital appointment'		
<b>Eigenvalue</b>	<b>3.53</b>	<b>2.66</b>
<b>Variance extracted (%)</b>	<b>13.06</b>	<b>9.87</b>

*Factor loadings less than .30 have been suppressed.*

Factor one had high loadings from variables measuring the perceived necessity of the appointment for the child's health; beliefs about personal outcomes of attending (feeling reassured and gaining a



better understanding of the health issue); attitudes regarding the importance and 'worth' of hospital doctors for treating children; attitudes regarding the experience of attending (pleasantness and convenience); and the perceived difficulty of getting to the appointment (in terms of travel, cost, taking time away from other commitments and getting the child to go). This factor was labelled 'perceived *worth* of attending the appointment'.

Factor two had high loadings from variables measuring anticipated anxiety while waiting in the waiting area; anticipated affect while with the doctor (anxiety and frustration); anticipated frustration while waiting in the waiting area; worry about having to go to the appointment; specific concerns about attending (being judged by the doctor or unwanted medicines being prescribed); dislike of hospital doctors; and a negative loading of anticipated feelings of relaxation while waiting in the waiting area for the appointment. This factor was labelled 'worry about attending the appointment'. Reliability analyses were conducted to test the internal consistency of each factor. Both had satisfactory Cronbach's alpha values (factor one  $\alpha=.753$ , factor two  $\alpha=.759$ ).

## **6.4 DISCUSSION**

### **6.4.1 Summary**

The aim of this quantitative questionnaire study was to investigate the underlying factors that explain and structure parents' beliefs about attending General Paediatric outpatient appointments. The findings of the exploratory factor analysis show that there are two predominant latent factors, the perceived 'worth' or value of the appointment and 'worry' associated with attending, including anticipated negative affect while visiting the clinic. These findings are compatible with the findings of the earlier qualitative phase which highlighted similar constructs: the perceived importance of the appointment and parents' perceptions about their ability to attend, which included concepts of stress, as well as barriers and facilitators. As anticipated, through the complementary use of qualitative and quantitative methods within a mixed methods design the findings presented here have enhanced the understandings gleaned from the earlier qualitative phase.

### **6.4.2 Relationship to the literature**

The findings of this exploratory factor analysis indicate that parents' beliefs about attending General Paediatric outpatient appointments cluster around two underlying constructs, the perceived worth of the appointment and worry associated with attending. Similar variables have been shown in previous research to be important predictive factors of attendance behaviour. For example, the value of appointments is partly determined by attitudes towards doctors, and several studies have investigated the link between this construct and healthcare use. A study of utilization of primary care

services by adults reported that frequent attendance was less likely in those with negative attitudes towards doctors (Little et al., 2001). Similarly, uptake of prenatal screening services was significantly predicted by attitudes towards doctors in a study by Marteau et al. (1992). However, other aspects of the perceived value of appointments have not yet been investigated, particularly in relation to children's hospital appointments, including perceived necessity of the appointment and experiential attitudes of attending. Moreover, very few studies have examined anticipated negative affect with regards to attending appointments, though Sheeran et al. (2007) found that anticipated 'affective costs' such as shame negatively affected attendance in a study of adult psychotherapy appointments. Much more research is required regarding anticipated affect and attendance across all healthcare domains, including General Paediatric care.

#### **6.4.3 Strengths and limitations**

This research was the first to use exploratory statistics to examine parental cognitions about attending children's hospital appointments and their underlying psychological factors. The study benefited from data collected from General Paediatric services at two sites, one a specialist children's hospital and the other a district general hospital. The two samples were equivalent across the majority of demographic and health service use variables, and there was a wide range of paediatric health conditions represented.

However, there were significant differences in parental employment status, level of education attained, and children's sex between the samples which could have influenced the findings. The differences were due to an unusually large percentage of the Birmingham Children's Hospital sample being educated to university level, and a disproportionate percentage of male children represented in the district general hospital sample. There were also significantly more participants in employment in the BCH sample, and significantly more participants not in paid work in the Heartlands Hospital sample. It was not possible to compare the distribution of education and employment variables in the samples versus the populations from which they were drawn, as this data was not recorded by either hospital. Yet it suggests that at BCH parents educated to a higher level were more likely to complete the questionnaire, perhaps due to greater experience with university-led research. This skew towards higher educational attainment would almost certainly have influenced the findings and further research with a more representative sample is therefore required.

Furthermore, the parents in the BCH sample were significantly different from the children in the population in terms of ethnicity with a greater proportion being 'white British', and they had children that were significantly older. These factors could also have contributed to bias in the data. In

contrast there was no difference found between the distribution of child sex in the Heartlands Hospital sample and population, indicating that the sample was representative on this variable. Yet the difference between samples could still have caused problems in analysis if parents' beliefs about attending appointments are influenced by the sex of the child.

Finally, the study was limited by poor recruitment at Heartlands Hospital. While the questionnaire response rate at BCH exceeded the required 12.5% and reached nearly a fifth of invited parents, the response at HH was very low at under 6%. The findings from this sample in particular should therefore be treated with caution, as the data is likely to be biased toward the views of parents who were willing or able to participate in research. The reasons for the low response rate at Heartlands Hospital are unclear, though it is possible that parents were less interested in assisting researchers based at a different hospital, or that they were less engaged with the General Paediatric service than parents at BCH.

#### **6.4.4 Implications**

The findings of this study have implications for both managing non-attendance in clinical practice and for future research. First, the results indicate the importance of addressing at least two main issues regarding parents beliefs and motivations about attending. In addition to appointment reminders and removal of barriers to accessing services, clinicians and managers must also consider strategies to increase the perceived value of appointments for families, and manage parental concerns about visiting the clinic including their anticipation of feelings of anxiousness and frustration. This may mean altering the ways in which services are provided, or introducing interventions that target these psychological factors directly.

Further research is required in order to test whether the two factors identified in this study are predictive of intention to attend an upcoming appointment, or of actual attendance. The predictive abilities of these and other variables were not addressed in this PhD due to time constraints, but also due to difficulties in measuring attendance as an outcome variable. There are several problems with the way in which non-attendance is recorded at BCH, as recording criteria are used inconsistently across the General Paediatric service and there is more than one code under which non-attendance can be recorded. Moreover, it may be unethical to access medical records and identify attendance behaviour without prior consent of the family, yet seeking permission to monitor future attendance may then influence that behaviour. Furthermore, intention was also shown in this study not to be a useful measure as there was very little variance in parents' responses on the intention questionnaire

items. These issues would need to be resolved before any future studies could be conducted using intention or attendance as outcome measures.

Finally, future studies are necessary in order to validate the questionnaire developed for this research. Study designs including tests of internal consistency of items within factors, predictive validity, test-retest reliability, construct validity (ability to differentiate between groups), criterion validity (correlation with existing validated measures), and the application of the questionnaire with different populations in different settings should all be considered.

#### **6.4.5 Conclusion**

This quantitative study employing questionnaire methods and an exploratory factor analysis has shown that parents' beliefs about attending upcoming General Paediatric outpatient appointments are structured according to at least two factors: the perceived value of the appointment, and the worry associated with attending. These findings suggest that attendance may be influenced by more than merely remembering the appointment and overcoming access barriers, but also parental cognitive factors. However, further research is required to test whether the identified factors predict attendance behaviour at children's hospital outpatient appointments.

## CHAPTER SEVEN

### 7. Discussion

#### 7.1 Introduction

This doctoral research project sought to examine the occurrence and management of non-attendance in General Paediatric outpatient clinics and investigate the parental factors associated with missing these appointments using a mixed methods approach. Non-attendance is prevalent with over 10% of paediatric appointments missed locally at Birmingham Children's Hospital (BCH) and nationally across England, and can have serious consequences for health service finances, family-doctor relationships, and children's health. However, research into causal or influencing factors of non-attendance had so far focused only on demographic, access and appointment related factors. The few studies investigating parents' reasons for missing appointments were descriptive and did not use trustworthy qualitative methods. Moreover, theories of cognition and behaviour had not yet been applied to attendance at children's hospital outpatient appointments. This PhD research was therefore necessary to fill gaps in the literature regarding current strategies for managing missed appointments and the psychological predictors of parental attendance behaviour.

This chapter will summarise the key findings of the thesis, compare and synthesise findings from the systematic review and three empirical studies, address the ways the findings relate to theory, present methodological considerations, and discuss implications for policy, practice and future research.

#### 7.2 Summary of the thesis

##### *7.2.1 Systematic literature review*

The aims of the systematic review were to document the range and type of interventions currently used to reduce non-attendance at General Paediatric outpatient clinics, to evaluate their effectiveness and to assess their theoretical foundations and incorporated behaviour change techniques.

It was found that few intervention studies had been published in the domain of General Paediatric secondary care, which accords with the conclusion of Sammons et al. (2004) that General Paediatrics is an under-researched area. There were substantially more studies that had been conducted in the United States, but these were not included in the review as the health service model in the US is

significantly different to the UK, with hospital-based paediatricians providing care that parents can access directly rather than through referral.

The majority of included studies presented evaluations of appointment reminder systems, including those delivered by text message, telephone, or by stickers given at the end of the last visit. A study of financial penalties for missed appointments was also reviewed, and two multi-component interventions which mainly targeted access barriers and parents remembering. None of the interventions had been designed using theory and only six different behaviour change techniques were identified, though most of the studies incorporated only two (giving information about performing the behaviour, and providing prompts or cues). Although the quality of evidence was only low to moderate, the findings indicated that appointment reminders sent by text message were likely to be effective in reducing non-attendance. However, future application of theory is necessary to establish the mechanism by which such reminders have their effects. Multi-component interventions showed some promise, but further research would be required to isolate beneficial effects that were not due to reminders alone. No interventions targeted parental factors such as beliefs or attitudes towards attending appointments.

### ***7.2.2 Qualitative study with healthcare providers***

The aim of this study was to use qualitative methods to explore healthcare providers' beliefs regarding the reasons for non-attendance at paediatric outpatient clinics and their views on how non-attendance should be managed.

Participants recognised the influence of access barriers and service-related factors, as well as parents' beliefs and motivations including perceptions of the child's illness and the value parents placed on their child's health. However, there were differences between GPs and hospital doctors in the factors they most emphasised. GPs focused on the difficulties faced by families attending appointments, while hospital staff were more attentive to parental motivations. Both primary and secondary care doctors perceived that non-attendance was more likely in 'chaotic' families due to poor organisational abilities, and hospital healthcare professionals characterised families as 'attenders' or 'non-attenders'.

GPs and managerial participants advocated management strategies that removed barriers to accessing services such as providing care closer to home. However, hospital doctors disagreed that this approach would improve attendance rates and instead advocated new ways of providing services and increased choice for families. Hospital-based interviewees also proposed educational strategies that raised awareness of the costs of missing appointments, ensured knowledge of the

reasons for appointments, and emphasised parents' rights and responsibilities regarding attendance. GPs were reluctant to interfere with parental decisions about attendance, but hospital staff were concerned with child safeguarding and subsequently more willing to intervene when appointments had been missed. Hospital-based healthcare professionals recognised the need to address parents' beliefs in order to improve attendance rates, but had no existing or feasible proposed interventions to do this beyond suggestions of 'educating' parents.

### **7.2.3 Qualitative study with parents**

The aim of this study was to identify the cognitive factors that influence attendance at General Paediatric outpatient appointments by examining parents' prior experiences of attending and missing appointments, and describing their values, attitudes, and beliefs in relation to attendance.

The findings indicated several issues that were important in determining parents' ability and motivation to attend, including: difficulties with planning and managing appointments; stressful factors when visiting the clinic; parents' evaluations of healthcare for their child; perceptions about the seriousness of the child's condition; beliefs about controlling the condition; and perceived responsibilities in relation to attending appointments.

Parents used different strategies and resources to manage appointments including appointment letters, reminders and telephone calls to the hospital, but hospital visits were nonetheless difficult to plan around other aspects of daily family life. Visiting the clinic was often stressful due to issues with transport and parking, worries about the clinic environment, problems managing child behaviour and parents feeling as though they did not know what to expect during the visit. Relationships with hospital consultants were often an important factor in determining parental motivation to attend, and the value parents placed on receiving paediatric care from a specialist centre also increased perceived importance of attending. Parents indicated that appointments were important for determining the seriousness of their child's condition and obtaining reassurance from the consultant, and also for controlling the condition through increased knowledge and medication. Finally, parents perceived that they had a responsibility to attend in order to meet their obligations as good parents and considerate health service users.

These qualitative findings suggest that two key cognitive factors may be important in determining attendance behaviour: parents' perceived ability to overcome difficulties and stressors to attend, and the perceived importance of attending.

### **7.2.3 Questionnaire study**

The aim of this study was to investigate the underlying factors that explain and structure parents' beliefs about attending General Paediatric outpatient appointments by designing a questionnaire to measure cognitive variables, conducting a survey of parents using the questionnaire, and carrying out an exploratory factor analysis on the collected data.

The analysis suggested two latent psychological factors underlying parents' beliefs about attending an upcoming appointment: the perceived 'worth' or value of the appointment, and 'worry' associated with attending. The former included items relating to the perceived necessity of the appointment, anticipated personal outcomes of attending, positive attitudes towards hospital doctors, attitudes regarding the experience of attending, and perceived difficulty of visiting the clinic. The latter factor included items relating to anticipated anxiety and frustration while visiting the clinic, worrying about going to the appointment, specific concerns about attending, dislike of hospital doctors, and belief that they would not be relaxed while waiting for their appointment in the clinic. These identified factors somewhat corroborate the qualitative findings from interviews with parents, though further research is required to validate the findings and the questionnaire.

### **7.3 Comparison and synthesis of findings**

The key finding from the systematic review was that appointment reminders sent by text message are likely to be effective in reducing non-attendance rates in General Paediatric outpatient clinics. Other potentially useful interventions included components that reduced barriers to accessing services. These approaches addressed some of the causal factors that healthcare providers identified in the first qualitative study, including parental 'disorganisation' and difficulties in visiting the clinic. However, no published interventions addressed parents' motivations or beliefs which healthcare staff recognised as an important issue influencing attendance.

The findings of the qualitative study with parents highlighted that although appointment reminders such as those evaluated in the systematic review may help in managing the planning and preparation for clinic visits, families already have several of their own strategies in place to prevent forgetting of appointments. Reminders are often valued as additional prompts to begin preparing for attendance. Parents also reported many other difficulties and stressors related to attending which were not addressed by the interventions included in the systematic review, including stressful aspects of being in the clinic environment. Neither were the two factors identified by the exploratory factor analysis targeted in any published intervention.



In comparing the findings of the two qualitative studies it is evident that healthcare professionals did recognise parents' perceptions of the seriousness of their child's condition as a relevant factor in determining attendance. However, healthcare staff did not consider the reasons why perceived seriousness improved attendance, as parents sought knowledge, reassurance and control over the condition. Interviews with parents clearly elucidated these perceived benefits of attending appointments for them and their children. Findings from the parent study also showed that staff members' views that non-attendance is caused by disorganisation or 'chaotic lifestyles' is oversimplified and unfair to parents who have to manage complex daily routines, the needs of multiple family members, child behaviour and worrying health conditions. Healthcare professionals recognised many of the individual difficulties faced by parents, but did not appreciate the sometimes overwhelming challenge of attending when these stressors are faced in combination. Moreover, healthcare staff did not much consider the experiences and feelings of parents during hospital visits, and the negative emotions they anticipate experiencing while in the clinic, which were highlighted by the questionnaire study.

The results of the questionnaire study complemented those described in the qualitative study with parents, though the specific components discussed were slightly different. The findings related to perceived value of the appointment in the interview study included benefits such as reassurance, knowledge and increased control of the child's illness. In the questionnaire study the included items were less specific, and incorporated these aspects using broader questions. For example, the desire to obtain reassurance by attending the appointment would be encapsulated by the questionnaire item measuring beliefs about personal outcomes. Similarly, the qualitative findings gave very specific examples of the issues that make attending appointments difficult and stressful. In contrast, the questionnaire items included in the factor regarding 'worry' measured predominantly the parents' feelings of anxiety, rather than the factors causing the stress. Thus, as anticipated, the two different methods gave complementary results with the qualitative study providing detailed information about parents' experiences while the quantitative study refined these findings into measurable factors.

#### **7.4 Relationship to theory**

The findings of this doctoral research demonstrate that it is possible and valuable to consider non-attendance at children's medical outpatient appointments from a psychological perspective, rather than merely one of service use. The findings fit well with the two models outlined at the beginning of the thesis. Andersen's (1995) Behavioural Model of Use of Health Services posits that service use, including attendance, is related to predisposing characteristics, enabling resources and health service need. The relationship between 'predisposing characteristics' such as employment and ethnicity, and

service use has not been investigated in this thesis. However, the findings presented herein match the other two factors well. Enabling resources include social and practical aspects that facilitate attendance at appointments, which map to the barriers and facilitators identified in the parent qualitative study. Andersen's (1995) concept of 'need' includes perceptions of health, symptoms, concerns, and worries, which have also all been mentioned in the qualitative study.

Additionally, the findings fit with the model of intentional and unintentional non-adherence. Unintentional non-attendance might include not receiving an appointment letter, or not understanding the communication with the hospital to know that an appointment has been scheduled. Intentional attendance might occur when perceived stressors are felt to be too much, for example choosing not to attend because of the known difficulties in accessing the hospital. However, neither of these broad models are sufficient to cover the range and depth of beliefs discussed by parents. The addition of other theories or theoretical literature is therefore necessary to adequately describe the complexity of factors that relate to parent's beliefs about appointments. The necessity and concerns framework proposed by Horne and Weinman (2002) as an extension to the Common-Sense Self-Regulation Model (Leventhal et al., 1998; 2003) presents similar factors in relation to medication adherence, but includes components that are not applicable to attendance at appointments. Moreover, the two main factors of necessity and concern are not broad enough to encompass all of the issues presented here.

## **7.5 Methodological considerations**

In the methodology chapter it was noted that the justification for using mixed methods for this doctoral research was to fulfil complementary purposes, using different methods to study different aspects of the same phenomenon. Given the paucity of research on the topic of psychological factors and non-attendance at paediatric hospital outpatient appointments, the use of a pragmatic mixed methods approach was most appropriate to investigate both parents' views and the factors underlying these views. The attainment of corroborating findings from the parent interview study and questionnaire study attest to the successfulness of this mixed methods design. Collecting the views of healthcare providers was also important in order to consider the ways in which staff perceptions about appropriate non-attendance management address the needs and concerns of parents.

The methods of data collection and analysis utilised in each study were also appropriate for achieving the aims of the thesis. For instance, the use of a wide range of databases for the systematic review and the lack of limitation of publication year ensured the inclusion of the largest possible number of

relevant papers for this under-researched topic area. Following the guidelines of a Cochrane Collaboration review group, including quality assessment criteria, was also advantageous for producing a high quality review as Cochrane represent the 'gold standard' in systematic reviewing. Semi-structured interviews were certainly the most suitable method of data collection for both qualitative studies as this approach provided flexibility to the participants in presenting what was important to them, but also ensured that the research questions were answered by guiding the interview. The thematic framework analysis used in both interview studies was also the best qualitative method to use given the large number of interviews conducted for each study. The indexing framework and matrix tools made sure that all aspects of the data were considered and that useful comparisons were made within and between interviews in order to establish patterns and themes. Postal methods were most appropriate for collecting questionnaire data from a large number of participants across more than one setting, and which may have been challenging to collect in person without affecting responses or causing discomfort. The anonymity of the postal approach was beneficial and may have supported the adequate response rate. Finally, the implementation of an exploratory factor analysis was fitting at this stage of research. Studies examining the predictive ability of parental cognitions in relation to attendance behaviour and motivation to attend are crucial to develop this field of research, but were not yet appropriate given the lack of prior empirical evidence, theory and suitable questionnaire measure. The factor analysis answered the given research question and refined the qualitative findings into an underlying psychological structure which can now be tested for its ability to predict behaviour.

Furthermore, it would not have been possible to investigate the prediction of attendance behaviour within the scope of this PhD due to difficulties in using attendance as an outcome measure, as mentioned in chapter six. The criteria by which to determine attendance or non-attendance are open to interpretation and differ according to the purpose of recording the behaviour, and by the person doing the recording. For example, in some instances a parent calling to cancel the appointment on the day that it is scheduled may still be considered a 'did-not-attend' if the recording guidelines stipulate a required notice period of 24 hours or more, as the appointment slot would not be available to any other families. There are also problems with attendance recording at Birmingham Children's Hospital due to an overly-complicated and counterintuitive coding scheme. There are multiple options under which non-attendance can be recorded and clinicians are inconsistent in their application of this coding index. Attendance data at BCH is therefore not reliable enough to be used in empirical research as a behavioural outcome measure, and much work would be required in collaboration with hospital managers, administrators and clinicians to resolve the issues and achieve high quality data. A final issue with using attendance as an outcome measure is that medical records

may need to be accessed or behaviour actively monitored both of which would ordinarily require explicit informed consent from the parent. Yet by seeking permission to record future attendance behaviour, this would very likely influence the behaviour in question and increase the likelihood that the family would attend, thereby invalidating the findings. This practical and ethical issue would also need to be resolved to progress with this research.

Just as the criteria for defining attendance are variable, so too are definitions of 'non-attenders' meaning families who frequently miss appointments. Healthcare professionals in the first qualitative study talked about these non-attending families and prior research has defined them according to different numbers of appointments missed over a given period, the frequency of appointments missed, whether non-attendances are consecutive, or in some studies simply whether a family attends a specified clinic visit. This highlights the difficulty in comparing findings across studies as different criteria may have been used.

The term 'non-attender' is also problematic as this concept does not accord with the experiences of parents. It was clear from interviews with parents that they would not have considered themselves a certain type of attender, nor characterised themselves as non-attenders. Instead they treated each attendance as an individual event for which challenges must be overcome as long as the anticipated outcome was perceived to be sufficiently positive. This may have contributed to the problems in recruitment described in chapter five (qualitative parent chapter), as in the later stages 'non-attenders' were sought explicitly, yet in hindsight this may be a false grouping which exists only to service providers and researchers rather than families themselves. Future studies should focus on attendance as a behaviour or event rather than a characteristic of parents and families, particularly in order to reduce unfair blaming of parents and negative attitudes towards them.

Another methodological learning point relates to recruitment methods used for the questionnaire study. Although an option was provided to complete the questionnaire online, only two participants chose to use this method. This is understandable as the invitation to participate was sent via post along with the paper version of the questionnaire. It was consequently easier to simply complete the form by hand and put it in the provided envelope instead of accessing a computer and typing in a lengthy web address. The paper form may also have acted as a visual reminder for parents to complete the survey. This observation will inform future research as time and money should not be spent on online versions of questionnaires unless the links to them can be sent to potential participants by email or other online methods.

Finally, there were a few issues with the representativeness of samples recruited for this research. Although there was diversity in age and ethnicity of parents in the qualitative study, only 3 out of 22 participants were male meaning that the views fathers may have been somewhat under-represented especially given that two of these fathers did not speak English as their first language and so may have given less detailed accounts of their perceptions and experiences. As discussed in chapter six there were also some differences in the sample of questionnaire participants from BCH as compared to Heartlands Hospital meaning that the findings are not yet transferable to other settings. The BCH sample, for example, had higher than expected levels of education and employment. Further research is therefore required to obtain a more representative sample on which to base findings and recommendations.

## **7.6 Implications**

### ***7.6.1 Implications for policy and practice***

The findings of this project have implications for clinical practice, health service policy, possible interventions and future research. It has been shown that GPs focus on access difficulties and are reluctant to interfere with parental decision-making. This means that at the time of referral there may be no attempt to alleviate worries about attending the hospital or to emphasise the importance and value of the appointment for children's health and parental responsibilities to attend appointments. Although missed appointments directly affect hospital consultants' time and clinic resources, GPs ought to take an interest in reducing secondary care 'did-not-attends' as they are cited in national guidelines as being directly responsible for the wellbeing of their child patients. GPs should therefore assist secondary care colleagues by discussing the importance of attending with parents and addressing any concerns about their hospital visit, particularly in the case of new referrals who have not previously had an outpatient appointment. This should be perceived as meeting the agenda of 'patient-centred care' as it would protect the rights of children to access health services in a timely manner, and should be seen as supporting parents to meet their parental responsibilities rather than interfering with their decision-making autonomy .

As a related issue, hospital consultants ought to expand their understanding of 'patient-centred care' to incorporate the informed choices and rights of parents as the means through which children's needs are best protected. Currently, hospital staff's dominant focus on child safeguarding means that there is sometimes a tendency to blame parents and view them negatively. Greater empathy for the challenge of balancing multiple complex family needs should be fostered. However, the focus should be on supporting parents to meet the needs and rights of the child within the family context, rather

than bowing merely to parental preferences. Hospital service providers must consider the experience of parents attending clinics and the negative emotions that are elicited through problems with travel, managing children, or coping with a clinic environment that is perceived as unpleasant or even dangerous. Non-attendance prevention strategies should include appointment reminders which are valued as additional prompts by parents, but should address other factors in addition to access difficulties. Increasing the perceived value of appointments and decreasing concerns about attending are essential objectives of any new strategies.

In terms of local policies, hospital services should amend DNA ('did-not-attend') guidelines to include planned methods for investigating the causes of non-attendance and implementing DNA reduction strategies rather than addressing merely follow up of missed appointments that have already occurred. This would further facilitate child protection by promoting their wellbeing through preventive approaches, instead of focusing on reactive responses to non-attendance triggers. Primary care centres should also consider adding guidelines regarding paediatric attendance at secondary care appointments to their DNA policies. As aforementioned, GPs have a responsibility to ensure that children receive the care they need. At the very least, these policies should provide explicit instructions for GPs when asked to follow up missed appointments by secondary care colleagues.

### ***7.6.2 Implications for future research***

This doctoral research has achieved the stated aims of examining the current management of missed appointments in General Paediatric services, and investigating parental psychological factors associated with non-attendance. Subsequent studies should now be planned that focus on further quantitative investigation of parental cognitions regarding attendance. The questionnaire used in the current research should be validated through tests of internal consistency within factors, test-retest reliability, construct validity, criterion validity and applying the questionnaire with different representative samples from alternative samples including other specialist children's centres and other district general hospital General Paediatric services. In the future the questionnaire could also be tested for use in other paediatric medical services including in primary and secondary care. It may be particularly interesting to investigate whether the identified factors are applicable in specialised services such as paediatric dental care, surgery, and mental health services.

Studies should then be conducted that examine whether the factors identified in the questionnaire study can predict attendance behaviour or intention to attend, though the aforementioned problems

with using attendance and intention as outcome measures must be resolved before this research can take place.

Finally, the findings of this research and future validating and predictive research should be used in research focusing on the development of evidence and theory-based interventions. If the factors and questionnaire can be validated then the constructs found to predict attendance ought to be targeted using appropriate behaviour change techniques that go beyond merely prompting or providing information. Once BCTs have been selected and developed into an intervention, a well-designed evaluation of the approach should be conducted and published in a report detailed enough to permit replication. BCTs that may be worth considering include techniques that focus on consequences of behaviour or anticipated regret which may work on the perceived value of the appointment; social comparison and information about others' approval which may increase perceived responsibilities for attending; comparative imagining of future outcomes which may target perceived value; rewards and incentives which may counteract concerns about attending; techniques that work on aspects of self-identity to emphasise attendance as a responsible parent and health service user; and techniques that focus on self-belief in order to overcome stress and difficulties of attending.

### **7.7 Concluding remarks**

By using a mixed methods approach and taking a Health Psychology perspective, this thesis contributes new knowledge to the literature on non-attendance at children's General Paediatric hospital outpatient appointments. A rich and detailed understanding has been obtained of parents' beliefs about attending appointments, and the foundations for future research have been set by elucidating the psychological factors underlying these beliefs. The next steps in the continuation of this research are to test the ability of the identified factors to predict non-attendance behaviour and to further test the questionnaire as a useful tool in healthcare research.

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## APPENDICES

### Appendix 1: Supplementary materials for systematic review

#### 1.1 Data extraction template

##### Data collection form

“Systematic review of interventions to reduce non-attendance at general paediatric outpatient appointments”

<b>Study ID</b> ( <i>surname of first author and year first full report of study was published e.g. Smith 2001</i> )

<b>Report IDs of other reports of this study</b> ( <i>e.g. duplicate publications, follow-up studies</i> )

#### 1. General Information

1. <b>Date form completed</b> ( <i>dd/mm/yyyy</i> )
2. <b>Name/ID of person extracting data</b>
3. <b>Report title</b>
4. <b>Report ID</b>
5. <b>Reference details</b>
6. <b>Publication type</b>

#### 2. Eligibility

Study Characteristics	Review Inclusion Criteria	Yes/ No / Unclear	Location in text
<b>7. Type of study</b>	Randomised trial		
	Non-randomised trial		
	Controlled before-after study <ul style="list-style-type: none"> <li>• Contemporaneous data collection</li> <li>• At least 2 intervention and 2 control clusters</li> </ul>		
	Interrupted time series <ul style="list-style-type: none"> <li>• At least 3 time points before and 3 after the intervention</li> <li>• Clearly defined intervention point</li> </ul>		
	Repeated measures study <ul style="list-style-type: none"> <li>• At least 3 time points before and 3 after the intervention</li> <li>• Clearly defined intervention point</li> </ul>		
<b>8. Participants</b>			
<b>9. Types of intervention</b>			

Study Characteristics	Review Inclusion Criteria	Yes/ No / Unclear	Location in text
10. Types of outcome measures			
11. Decision:			
12. Reason for exclusion			
13. Notes:			

**DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW**

#### Population and setting

	Description	Location in text
14. Population description		
15. Setting		
16. Inclusion criteria		
17. Exclusion criteria		
18. Method/s of recruitment of participants		

#### 3. Methods

	Descriptions as stated in report/paper	Location in text
19. Aim of study		
20. Design		
21. Unit of allocation		
22. Start date		
23. End date		
24. Duration of participation		

#### 4. Risk of Bias assessment

Domain	Risk of bias	Support for judgement	Location in text
25. Random sequence generation			
26. Allocation concealment			
27. Blinding of participants and personnel			
28. Blinding of outcome assessment			
29. Incomplete outcome data			
30. Selective outcome reporting?			
31. Other bias			



## 5. Participants

Provide overall data and, if available, comparative data for each intervention or comparison group.

	Description as stated in report/paper	Location in text
32. Total no. randomised		
33. Clusters		
34. Baseline imbalances		
35. Withdrawals		
36. Age		
37. Sex		
38. Race/Ethnicity		
39. Socio-economic status		
40. Illness characteristics		
41. Interaction with service		
42. Other treatment received		
43. Other relevant sociodemographics		
44. Subgroups measured		
45. Subgroups reported		

## 6. Intervention groups

### Intervention Group 1

	Description as stated in report/paper	Location in text
46. Group name		
47. No. randomised to group		
48. Intervention aim		
49. Description		
50. Duration of treatment period		
51. Timing		
52. Delivery		
53. Providers		
54. Co-interventions		
55. Economic variables		
56. Resource requirements to replicate intervention		

## 7. Outcomes

### Outcome 1

	Description as stated in report/paper	Location in text
57. Outcome name		
58. Time points measured		
59. Time points reported		
60. Outcome definition		
61. Person measuring/ reporting		
62. Method of assessing outcome		
63. Unit of measurement		
64. Scales: upper and lower limits		
65. Is outcome/tool validated?		
66. Imputation of missing data		
67. Assumed risk estimate		

## 8. Results

### For randomised or non-randomised trial - Dichotomous outcome

	Description as stated in report/paper	Location in text			
68. Comparison					
69. Outcome					
70. Subgroup					
71. Time point					
72. Results <i>Note whether: post-intervention OR change from baseline And whether Adjusted OR Unadjusted</i>	<b>Intervention</b>		<b>Comparison</b>		
	No. events	No. participants	No. events	No. participants	
73. Baseline data	<b>Intervention</b>		<b>Comparison</b>		
	No. events	No. participants	No. events	No. participants	
74. No. missing participants and reasons					
75. No. participants moved from other group and reasons					
76. Any other results reported					
77. Unit of analysis					

	Description as stated in report/paper		Location in text
78. Statistical methods used and appropriateness of these methods			
79. Reanalysis required?			
80. Reanalysis possible?			
81. Reanalysed results			

*For controlled before-after study*

	Description as stated in report/paper				Location in text
82. Comparison					
83. Outcome					
84. Subgroup					
85. Timepoint					
86. Post-intervention or change from baseline?					
87. Results	Intervention result	SD (or other variance)	Control result	SD (or other variance)	
	Overall results		SE (or other variance)		
88. No. participants	Intervention		Control		
89. No. missing participants and reasons					
90. No. participants moved from other group and reasons					
91. Any other results reported					
92. Unit of analysis					
93. Statistical methods used and appropriateness of these methods					
94. Reanalysis required?					
95. Reanalysis possible?					
96. Reanalysed results					

**9. Applicability**

97. Have important populations been excluded from the study?		
98. Is the intervention likely to be aimed at disadvantaged groups?		
99. Does the study directly address the review question?		

**10. Other information**

	Description as stated in report/paper	Locatio
100. Key conclusions of study authors		
101. References to other relevant studies		

## Appendix 2: Supplementary materials for the qualitative study with parents

### 2.1 NHS Research Ethics Committee approval confirmation

	 <b>National Research Ethics Service</b> <b>West Midlands Research Ethics Committee</b> Prospect House Fishing Line Road Enfield Redditch B97 6EW nikki.murphy@westmidlands.nhs.uk Chairman: Mr Paul Hamilton
	Telephone: 01527 582 533 Facsimile: 01527 582 540
12 November 2010	
Dr Carole Cummins Senior Lecturer Institute of Child Health Whittall Street Birmingham B4 6NH	
Dear Dr Cummins	
<b>Study Title:</b>	<b>Paediatric Location and Care Evaluations (PLACES): A qualitative evaluation of parent, child and adolescent views of general paediatric satellite clinics in terms of space, place, access and attendance.</b>
<b>REC reference number:</b>	<b>10/H1208/58</b>
Thank you for your letter of 09 November 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.	
The further information has been considered on behalf of the Committee by the Chair	
<b>Confirmation of ethical opinion</b>	
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.	
<b>Ethical review of research sites</b>	
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).	
<b>Conditions of the favourable opinion</b>	
The favourable opinion is subject to the following conditions being met prior to the start of the study.	
This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England	

## 2.2 Aston University Life & Health Sciences Research Ethics Committee approval confirmation



Aston Triangle  
Birmingham B4 7ET  
United Kingdom  
Tel +44 (0)121 204 3000

[www.aston.ac.uk](http://www.aston.ac.uk)

### Memo

To: Prof Helen Patterson  
Cc: Rachel Moorhouse, administrator to the Life and Health Sciences Research Ethics Committee;

From: Dr Anthony Cox  
Chair of the Life and Health Sciences Research Ethics Committee

Date: 15/2/2011

Subject: **Qualitative study of parents' views and experiences of access and attendance at paediatric outpatient appointments in hospital and community settings**

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Dear Helen,

The above proposal has been reviewed by a sub-group of the LHS Research Ethics Committee.

**Outcome:** Favourable (study can proceed)

I would also like to pass on the comments of one of the committee:

*I would like to commend Elaine on the design of her information sheets and consent form. They are clear and definitely more attractive than the standard A4 sheets of paper we usually distribute.*

Good luck with your research.

Yours sincerely,

## 2.3 Participant invitation letter



UNIVERSITY OF  
BIRMINGHAM



PLACES Project  
Institute of Child Health  
Whittall Street  
Birmingham  
B4 6NH  
Tel: 0121 333 8748

Dear Family,

We are researchers at Birmingham Children's Hospital and the University of Birmingham. We are carrying out a project called PLACES: Paediatric Location And Care Evaluations. This project is evaluating general paediatric outpatient services provided by Birmingham Children's Hospital (BCH).

We intend to include the views of parents, children and young people in this project and would like to invite you to take part. You can do this by participating in a one-to-one interview or in a group discussion about BCH outpatient services. This will take about 1 hour to complete and will include asking about your views on where and how general paediatric outpatient services should be delivered.

Children and young people can also take part by participating in a discussion group run at the same time as parent discussion groups. There will be a range of arts activities for children and young people to get involved in and they will receive a £10 Love2shop voucher for taking part.

Refreshments will be provided for all and travel expenses reimbursed. Interview data will only be used for the purpose of this project and participants will not be personally identifiable in any reports.

We would very much appreciate your help with this work and have included an information sheet for your interest. If you would like to participate please complete the enclosed contact information form and return it in the pre-paid envelope supplied. Alternatively you can contact us by telephone: 0121 333 8748 or email: [gina.carrelli@bch.nhs.uk](mailto:gina.carrelli@bch.nhs.uk)

We look forward to hearing from you.

Yours sincerely,

Gemma Heath and Elaine Cameron

## 2.4 Participant information sheet

### What will happen to the recordings?

Voice recordings will be put onto a laptop computer and then stored on a secure server. Recordings will then be deleted from the recorder and from the laptop. They will be transcribed and analysed by the researchers and then transcripts will be stored in a locked cabinet, in a locked room. Data will only be used for the purpose of this project.

### Do I have to take part?

No, participation is voluntary. You may withdraw from the project without giving a reason at any time. If you decide to withdraw, all data that has been collected from you will be deleted.

### Are there any benefits or disadvantages to taking part?

There are no specific benefits to taking part in this project. However, the results of the project may influence the way in which BCH paediatric services are delivered in the future. You will not be disadvantaged by participating in this project.

### Will my participation in the study be confidential?

Yes. When we transcribe the interviews, all participants will be given a code name so that they cannot be identified from the report. Any other personal information will also be removed from the transcripts.

### What happens after the study?

We will feedback findings to all participants at the end of the project. You will be able to access findings on a website, on posters at BCH and by attending project events.



**National Institute for  
Health Research**



You are invited to participate in the CLAHRC PLACES project, carried out by researchers from Birmingham Children's Hospital and University of Birmingham.

Before deciding whether you would like to take part, please read the following information about the project and what participation will involve.

Thank you for taking the time to read this information sheet.

#### **What is CLAHRC?**

NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) are partnerships between NHS Trusts and Universities. CLAHRCs were established to undertake applied health research focused on the needs of patients and to support the translation of research evidence into NHS practice.

#### **What is the PLACES project?**

As part of the CLAHRC project for Birmingham and Black Country, we are evaluating where and how Birmingham Children's Hospital provides general paediatric outpatient services. In particular we are interested in the location and design of general paediatric outpatient services.

Your views as a parent are important for helping us to develop outpatient services which meet your needs and wishes.

#### **If I take part, what will it involve?**

**What:** Interview or group discussion about outpatient services.

**How long:** 1 1/2 hours.

**Where:** BCH or University of Birmingham or your home.

**How:** We will record what you have to say on a digital recorder.

**Can I bring my children?** Yes, we will be running groups for children and young people at the same time as parent groups.

If your child would like to take part, please bring them along.

## 2.5 Letter for recruiting through existing participants

 UNIVERSITY OF  
BIRMINGHAM

  
Birmingham  
Children's Hospital

  
**THANK YOU**

PLACES Project  
Institute of Child Health  
Whitall Street  
Birmingham  
B4 6NH

Mobile: 07770 701 908  
Tel: 0121 333 8748  
Email: [e.l.cameron@bham.ac.uk](mailto:e.l.cameron@bham.ac.uk)

Dear Parent,

Thank you very much for helping our research by taking part in an interview last year with Gemma or Elaine. The information that you and other families provided has been extremely helpful.

We have been evaluating the information and will share the findings with the hospital. The final reports of the research will be available to you when the studies are complete. If you would like to receive this information, please get in touch using the details above.

*We have now finished our main set of family interviews. However, I would still like to talk to parents of children who have been referred for a general paediatric appointment at Birmingham Children's Hospital, but were either unable or chose not to go to the appointment. This will tell us more about the difficulties families face and their decisions about healthcare, which we hope will lead to improved services.*

If you know anyone like this, please ask them if they might like to take part, and to contact me on: **07770 701 908** by call or text message, or using the details above. Some further information about the research is provided on the back of this letter.

Again, many thanks for taking part in our research and we wish you all the best.

Yours sincerely,

## 2.6 Letter for recruiting through GP practices



PLACES Project  
Institute of Child Health  
Whitall Street  
Birmingham  
B4 6NH

Mobile: 07770 701908

Tel: 0121 3338748

Email: [e.l.cameron@bham.ac.uk](mailto:e.l.cameron@bham.ac.uk)

26<sup>th</sup> September 2012

Dear Sir/Madam,

I am a researcher at Birmingham Children's Hospital and the University of Birmingham, working on a project called PLACES (Paediatric Location And Care Evaluations).

I am currently investigating reasons for missed children's hospital appointments by interviewing parents who have recently been referred to Birmingham Children's Hospital, but were either unable or chose not to go. I hope that this research will help to ensure high quality services for children and families, and efficient processes in primary and secondary care.

***Could you please consider assisting this research simply by displaying the enclosed poster and stickers together in your reception area where they might be seen by parents?***

I would very much appreciate your help with this project. If you have any questions or would like more information, please contact me using the details above.

Yours sincerely,

## 2.7 Personalised recruitment letters to non-attending parents



UNIVERSITY OF  
BIRMINGHAM

Dear parent of [**NAME OF CHILD**],

I am a researcher at Birmingham Children's Hospital and the University of Birmingham, working on a project called **PLACES** (Paediatric Location And Care EvaluationS).

I am interested in finding out why some families miss their first appointments at Birmingham Children's Hospital. This will tell me about the difficulties families face and their decisions about healthcare, which I hope will lead to improved services for families at the hospital.

I note that your child was scheduled to attend the hospital on [**DATE**] at [**TIME**], but did not come to the appointment. I would be very interested to talk to you about your views and the reasons that led to this appointment being missed.

*If you did not know about this appointment, please contact the hospital for help to rearrange your appointment and to make sure they can contact you in the future.*

*This research is **not** connected to you or your family's appointments or healthcare in any way. Talking to me would be confidential and for my research only. I will not share the information you give me with your doctors or anyone else.*

I would very much appreciate your help with this project. Please read the information on the back of this letter about taking part, then contact me on: **07770 701 908**, by returning the contact slip in the envelope provided, or by using the details above.

Alternatively you can text the word RESEARCH and your name to **07770 701 908** and I will call you back with more information and to discuss taking part.

Yours sincerely,

Elaine Cameron  
(PLACES Project Doctoral Researcher)



## 2.8 Interview guide

*To explore the factors that impact on access and attendance at general paediatric outpatient appointments at BCH and satellite clinics.*

- 1. Could you tell me a bit about your family?**
  - Number of children, how old they are
  - Is there anyone else involved in caring for the children?
- 2. Could you tell me about your child's condition?**
  - Symptoms?
  - How long have they had the condition?
  - Is it chronic or recurring?
  - How serious do you feel their condition is?
- 3. What led to your child having a general paediatric outpatient appointment at Birmingham Children's Hospital?**
  - Who requested the appointment (e.g. GP or parent)?
  - How easy or difficult was it to schedule an appointment?
- 4. How do you feel about the communication you've had with BCH?**
  - Is it easy to contact them, change appointments?
  - Calls, letters?
- 5. How long did you have to wait for the appointment?**
  - Was this an acceptable time to wait?
  - What would you have done if you couldn't get an appointment in the timescale you'd like?
- 6. How is their condition being managed or treated now?**
  - Contact with GP?
  - Any other professionals involved?
  - How well do you feel your child's condition is being managed?
  - How able do *you* feel in managing your child's condition?
- 7. Can you tell me about the number of appointments your child has had at BCH for this condition?**
  - When was their first appointment?
  - How many follow-up appointments have they had?
  - How often are their appointments?
- 8. Have been to BCH for any other reason?**
  - Different condition, other children, other services?
  - Emergency department?
- 9. What is it like coming to BCH for appointments?**
  - The journey, waiting area, reception, consultation
  - Who usually comes with the child?
  - How easy or difficult is it to go there? What makes it easy/difficult?
  - How do you overcome these difficulties?
  - How comfortable are you going there/ how do you feel when you have to go for an appointment?

- 10. How does your child feel about coming to BCH for outpatient appointments?**
  - How do they behave?
  - Does that influence how you feel about coming for the appointment?
- 11. What do you think of the location of BCH?**
- 12. What do you think of general paediatric outpatient appointments being delivered in other settings, such as GP practices or children's centres?**
- 13. What would it be like for you to go to a BCH appointment at a GP practice or a children's centre in your area?**
  - How would you feel about having an appointment there?
  - How do you think other families might feel?
  - In what ways would it be easier or more difficult to attend than BCH?
  - How would your child react?
- 14. How would you feel about having an outpatient appointment outside of normal hours?**
  - Evening, early morning, weekend
  - Is it easier or more difficult during school holidays?
- 15. Has your child ever missed one of their outpatient appointments?**
  - Tell me about the time or times that they missed their appointment.
  - What were the reasons for missing the appointment?
  - How did you feel when your child has missed their appointment?
  - What happened after they missed the appointment (consequences, re-referral)?
- 16. How important do you think it is for your child to attend their outpatient appointments?**
- 17. What might make you decide not to attend an appointment?**
- 18. Are there any other reasons that might make you miss an outpatient appointment?**
- 19. Why do you think other families miss Birmingham Children's Hospital outpatient appointments?**
- 20. Do you think BCH should try to prevent people missing appointments?**
  - How might they do this?
- 21. Is there anything that you would like to add?**

## 2.9 Example of a theme matrix

	2.a. Views on being a parent	2.b. Attitude to the child, their health and care
P21	<p><i>(Re. getting time off work for child appt)</i>            FATHER: Got parents not putting themselves forward to do exactly what they should be doing.</p>	<p>FATHER: <u>If child's not feeling very fine, technically I'm not very fine too. If she's fine and happy, then I'm fine. [QQ]</u></p> <p><i>(Re. prefer to stay out of hosp)</i>            MOTHER: If could keep children healthy and self healthy that would be perfect, but doesn't work like that.</p>
P22	<p><u>'As a parent you can be a little bit more pushy (than grandmother), can't you?'</u> <i>(re. getting answers)</i></p> <p><i>(Re. managing children during interview)</i> With 3 boys, <u>got to have a bit of discipline!</u></p> <p><u>'If I'm not happy, child's not happy. If a mum's not happy, child isn't. If I'm confident, can then instil confidence in child.'</u> <i>[compare P21, 2b]</i></p> <p><u>As a parent have big influence on children.</u> <i>(re. choosing to see paed psych or not)</i></p>	<p>Would do <u>whatever takes to get child on road to recovery.</u> [QQ]</p> <p>Mother of 3 lads who play rugby, get knocks and colds. <u>Can't overreact on every snuffle. Would be a nervous wreck.</u> But as parent you <u>just know (when something is wrong)</u>. Just knew, but couldn't put finger on it.</p>

QQ: denotes a quote felt to be interesting for quotation





### 3.2 Final questionnaire instrument content

**“Going to General Paediatric Appointments – A Questionnaire Study”**

Which charity would you like your £1 to go to, as a thank you for completing this questionnaire?  
Birmingham Children’s Hospital Charity                      NSPCC                      Save the Children

Please write today’s date here:

Is your child’s hospital appointment within the next two weeks?      Yes              No

1      What age is your child?

2      Is your child:      Male      Female ?

3      What health issue is the hospital appointment for? (Please write your answer in this box)  
Please tell us about any other health issues later in the questionnaire at question 28.

4      Has your child seen a GP (General Practitioner) for this health issue?      Yes      No  
If you answered YES, please answer this question:

    a.      How would you rate your child’s visits to the GP for this health issue?  
            Poor                      Excellent

5      a.      In general, how would you rate the personal manner of your child’s GP? (e.g. respect, friendliness)  
    b.      In general, how would you rate the medical competence of your child’s GP? (e.g. knowledge, thoroughness)  
            Poor                      Excellent

6      Which of these urgent care services have you used for this health issue for this child? (Please tick all that apply)  
            Emergency department  
            Minor injury unit  
            Walk-in centre  
            GP out of hours service  
            Other (please state):  
            None of these

7      Has your child already seen the hospital General Paediatric service for this health issue?  
            Yes                      No  
If you answered YES, please answer these questions:

    a.      Overall, how would you rate your child’s visits to the General Paediatric service?  
    b.      How would you rate the personal manner of the hospital doctor? (e.g. respect, friendliness)  
    c.      How would you rate the medical competence of the hospital doctor? (e.g. knowledge, thoroughness)  
    d.      How would you rate the length of time waiting in the waiting area to see the hospital doctor?  
            Poor                      Excellent

8      Did you ask for your child to have a hospital appointment for this health issue?  
            Yes                      No, it was suggested by a GP or other health professional

9      Who arranged for your child to have a hospital appointment for this health issue?  
            A GP (General Practitioner)  
            A doctor in the emergency department  
            Another health professional (please say who):

10      How would you rate the length of time waiting for the upcoming hospital appointment?  
            Poor                      Excellent

11      Do you think that you personally will go with your child for the hospital appointment?  
            Yes                      No, someone else will go to the appointment with the child  
If you answered YES, please rate how strongly you feel about attending on a scale of 1 to 5:  
    a.      I want to attend the appointment


	b.	I intend to attend the appointment		
		Strongly disagree		Strongly agree
12		On a scale of 1 to 5, attending my child's hospital appointment would be:		
	a.	Worthless		Useful
	b.	Unpleasant		Pleasant
	c.	Inconvenient		Convenient
	d.	Unimportant		Important
13	a.	Attending the hospital appointment will make my child's health issue better		
	b.	Attending the hospital appointment will stop my child's health issue becoming worse		
	c.	My child's current health depends on attending the hospital appointment		
	d.	My child's future health depends on attending the hospital appointment		
		Strongly disagree		Strongly agree
14		If I attend my child's hospital appointment:		
	a.	I will be given advice or support to manage the health issue		
	b.	My child will receive treatment for the health issue		
	c.	I will better understand my child's health issue		
	d.	It will make me feel reassured		
		Very unlikely		Very likely
15	a.	Having to go to the hospital appointment worries me		
	b.	I worry that the doctor will prescribe a medicine or treatment I don't agree with		
	c.	I worry that the doctor will judge me for my child's health issue		
		Strongly disagree		Strongly agree
16		While waiting in the waiting area for the appointment, how much do you think you would feel these emotions?		
	a.	Relaxed		
	b.	Anxious		
	c.	Frustrated		
		Not at all		Very much
17		When you are with the doctor during the appointment, how much do you think you would feel these emotions?		
	a.	Relaxed		
	b.	Anxious		
	c.	Frustrated		
		Not at all		Very much
18	a.	I am confident that I could attend my child's hospital appointment		
	b.	I am completely in control of whether I go to the hospital appointment or not		
	c.	I feel that I had a choice about the time of the hospital appointment		
		Strongly disagree		Strongly agree
19		How easy or difficult would you find each of these parts of attending the hospital appointment?		
	a.	Remembering the appointment		
	b.	Taking time away from other responsibilities		
	c.	Getting your child to go to the appointment		
	d.	Having the money to go to the appointment		
	e.	Travelling to the appointment		
	f.	Checking in at the reception desk		
	g.	Managing your child/children's behaviour		
	h.	Asking the doctor questions		
	i.	Telling the doctor your concerns		
	j.	Understanding what the doctor tells you		

		Very difficult	Very easy
20		How much do you feel you could get practical help from someone close to you to attend your child's hospital appointment if you needed it?	
		Not at all	Very much
21	a.	I feel under social pressure to attend my child's hospital appointment	
	b.	My family and friends think I should attend my child's hospital appointment	
	c.	My child's GP (General Practitioner) thinks I should attend the hospital appointment	
	d.	Other parents like me would attend their child's hospital appointment	
	e.	Attending my child's hospital appointment would be the right thing to do	
		Strongly disagree	Strongly agree
22		If I did not attend my child's hospital appointment:	
	a.	I would have to wait a long time for another one	
	b.	I would feel guilty	
	c.	The doctor's time would be wasted	
	d.	It wouldn't be fair on other families	
	e.	I would not be meeting my responsibilities as a parent	
		Strongly disagree	Strongly agree
23		Which of these methods do you use to remember your child's hospital appointments? (Tick all that apply)	
		Electronic reminder or alarm	
		Storing the letter safely	
		Calendar or diary	
		Phoning the hospital to check	
		Someone else remembering	
		Reminders from the hospital	
		Other (please state):	
24		This question is about your views on hospital doctors IN GENERAL.	
	a.	If a child is sent to see a hospital doctor it must be important	
	b.	Hospital doctors know what's best for children	
	c.	I don't like hospital doctors	
	d.	No matter how long you have to wait to see a hospital doctor, it's worth it	
		Strongly disagree	Strongly agree
25		Thinking about the health issue that the hospital appointment is for, in the past 4 weeks:	
	a.	How much physical pain due to the health issue has your child experienced?	
		None	A mild amount
		A moderate amount	A severe amount
	b.	How much emotional upset because of the health issue has your child has experienced?	
		None	A mild amount
		A moderate amount	A severe amount
26		Thinking about the impact of this health issue on your child's daily life in the past 4 weeks, how have things been going for them?	
		Very badly	Very well
27	a.	This health issue is a serious condition	
	b.	This health issue doesn't make any sense to me	
	c.	There are cycles when the health issue gets better and worse	
	d.	There is nothing medically that can help the health issue	
	e.	The health issue does not have much effect on my child's life	
	f.	My child having this health issue makes me feel anxious	
	g.	I can affect whether the health issue gets better or worse	
	h.	The health issue will last a short time	
	i.	The health issue can be improved with treatment	



### 3.3 Ethical and research approval confirmations

#### 3.3.1 NHS Research Ethics Committee approval

  
**Health Research Authority**  
**National Research Ethics Service**

**NRES Committee Yorkshire & The Humber - Humber Bridge**  
HRA NRES Centre North West  
Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3JZ  
  
Telephone: 0161 625 7816  
Facsimile: 0161 625 7299

30 August 2013

Miss Elaine Cameron  
PhD Student and Health Psychologist in Training  
Birmingham Children's Hospital NHS Foundation Trust  
90 Vincent Drive, School of Health & Population Sciences  
University of Birmingham  
Edgbaston, Birmingham  
B15 2SQ

Dear Miss Cameron

**Study title:** A questionnaire study investigating parents' beliefs about attending children's General Paediatric hospital outpatient appointments

**REC reference:** 13/YH/0297

**Protocol number:** EC001

**IRAS project ID:** 136504

The Proportionate Review Sub-committee of the NRES Committee Yorkshire & The Humber - Humber Bridge reviewed the above application on 28 August 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Diane Catterall, [nrescommittee.yorkandhumber-humberbridge@nhs.net](mailto:nrescommittee.yorkandhumber-humberbridge@nhs.net).

**Ethical opinion**

You clarified the following for the Committee:

1. No serial numbers will be used on the returned questionnaires
2. Invitations will only be sent to parents, not directly to young people
3. Statement added to the information sheet that the research is part of a student PhD project
4. Statement added to the information sheet requesting that participants do not write their name or signature on the forms so will not break anonymity

Revised invitation letter and participant information sheet submitted.

A Research Ethics Committee established by the Health Research Authority

### 3.3.2 Aston University Life and Health Sciences Research Ethics Committee approval



Aston Triangle  
Birmingham B4 7ET  
United Kingdom  
Tel: +44 (0)121 204 3000  
[www.aston.ac.uk](http://www.aston.ac.uk)

Elaine Cameron  
Research Student  
School of Life and Health Sciences

26<sup>th</sup> September 2013

Dear Elaine

**Re: Project:** *"A questionnaire study investigating parents' beliefs about attending children's general paediatric hospital outpatient appointments"*

**Aston University Sponsorship Reference Number:** 057S/EC

I am writing to confirm Sponsorship for your project on behalf of the University Research Ethics Committee.

This approval is subject to:


- Undertaking the project as described in the Protocol
- Using the supporting documents listed below
- Participation of staff and students as described below
- The project being undertaken in conjunction with the NHS sites listed below
- Formal approval of any amendments' including personnel changes
- Adverse event and serious adverse event reporting
- Provision of annual reports

Amendments to the Project

Any proposed amendments to the project (including personnel) must have both the required regulatory approvals (normally NHS Research Ethics Committee) and Aston University Research Ethics Committee approval prior to implementation.


Approval of Aston University Research Ethics Committee should be sought by e-mailing details of the amendment to [ahricgovernance@aston.ac.uk](mailto:ahricgovernance@aston.ac.uk).

### 3.3.3 Birmingham Children's Hospital NHS Foundation Trust R&D approval

<b>Birmingham Children's Hospital</b> 	
NHS Foundation Trust	
<b>DIRECTORATE OF RESEARCH AND DEVELOPMENT</b>	
<b>Research and Development Office</b>	Steelhouse Lane
Direct Line: 0121 333 8714/8731	Birmingham
Fax No: 0121 333 8715	B4 6NH
	Tel: 0121 333 9999
	Fax: 0121 333 9998
Our Ref: KR/SP/R&D Approval	
19 September 2013	
Miss E Cameron Health Psychologist in Training Birmingham Children's Hospital NHS Foundation Trust 3 <sup>rd</sup> Floor Institute of Child Health Steelhouse Lane Birmingham B4 6NH	
Dear Elaine	
<b>Re: Birmingham Children's Hospital NHS Foundation Trust R&amp;D Approval</b>	
<b>Project Title: A questionnaire study investigating parents' beliefs about attending children's general paediatric hospital outpatient appointments.</b>	
<b>REC Ref:</b>	13/YH/0297
Thank you for complying with the Birmingham Children's Hospital NHS Foundation Trust's R&D approval process.	
I am now happy to approve the above study. You will note from the Research Ethics Committee (REC) approval letter dated 30 August 2013 that the favourable opinion is subject to obtaining management permission or approval at each host organisation prior to the start of the study. This letter constitutes that approval.	
Approval of the study is subject to the following conditions:	
<ol style="list-style-type: none"><li>1. That you inform the R&amp;D Office and the REC of any significant protocol amendments, sending copies of correspondence with the REC and also sending us copies of your REC annual progress and safety reports</li><li>2. That you notify the R&amp;D Office and the Governance Support Unit of any adverse events arising from this piece of research</li><li>3. That you provide the R&amp;D Office with interim reports as requested by the R&amp;D Office and a final report of your research</li><li>4. That you conduct the research in conformity with the Research Governance Framework and with clinical trials legislation where applicable.</li></ol>	
Yours sincerely	

### 3.3.4 Heart of England NHS Foundation Trust R&D approval

**Research & Development Directorate**



**MIDRU**  
Medical Innovation Development Research Unit  
Office Hours (Mon-Fri): 09.00 – 17.00  
Tel: 0121 424 1633  
Fax: 0121 424 3167  
Head of Research & Innovation: Bethan Bishop  
R&D Manager - Governance & Operations: Elizabeth Adey  
R&D Manager - Finance & Facilities: Rachel Ward  
Please send e-mails via [firstname.surname@heartofengland.nhs.uk](mailto:firstname.surname@heartofengland.nhs.uk)



**HEART of ENGLAND**  
NHS Foundation Trust

*Birmingham Heartlands Hospital*  
Bordesley Green East  
Birmingham B9 5SS

Tel: 0121 424 2000  
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25/10/2013

Dr Roopa Mulik  
Heart of England NHS Foundation Trust  
Birmingham Heartlands Hospital  
Bordesley Green Road East  
Birmingham  
B9 5SS

Dear Dr Roopa Mulik

**R&D Code: 2013084PD Re: Study title: A questionnaire study investigating parents' beliefs about attending children's General Paediatric hospital outpatient appointments**

**EudraCT: N/A**

I am pleased to inform you that the R&D review of the above project is now complete and has been formally approved to be undertaken at the following sites within Heart of England NHS Foundation Trust.

**Birmingham Heartlands Hospital      Research Site**

The following documents were reviewed:

- Protocol      Version 1 31 July 2013
- PIS      Version 2 23 August 2013
- GP letter      N/A
- NHS NRES Application Form      E Cameron 15 August 2013
- NRES Site Specific Information Form      Dr R Mulik (not dated)
- NRES Approval Letter      30 August 2013**
- SSI Approval Letter incorporated into Trust Approval**
- MHRA notice of Acceptance N/A**

Any Standard Operating Procedures for the Study

Other documents:

- Letter of Invitation to participant – HEFT Version 2 23 August 2013
- HEFT questionnaire instruction and comment sheet Version 1 25 July 2013
- Email confirming REC letter is not conditional 15 October 2013



### 3.4 Participant documents

#### 3.4.1 Invitation letter

Dear parent of [NAME OF CHILD],

We are doing a **questionnaire study** of parents' views and beliefs about going to children's General Paediatric appointments at Birmingham Children's Hospital (BCH), including parents of children who have been before and children who will soon be going for the first time.

**For every completed questionnaire we receive we will donate £1 to a children's charity.** Parents who return the questionnaire can choose whether their £1 goes to Birmingham Children's Hospital (BCH), the National Society for Prevention of Cruelty to Children (NSPCC), or Save the Children who do work in the UK and abroad.

We are asking you and other parents like you to take part because your child has a General Paediatric hospital appointment scheduled within the next two months.

*If you have recently cancelled the appointment or changed the date so it is no longer within the next two months, or if you have already had the appointment and do not have another scheduled in the next two months, then please ignore this letter and do not send back the questionnaire.*

*If you are unsure if your child has an appointment coming up then please call the Appointments team at BCH on 0121 333 9700, or the phone number given on your most recent appointment letter.*

Please **read the box on the back of this letter for more information** about the study. If you think you could help our research by filling out the questionnaire then please complete the form and return it in the envelope we have provided or go to [WEB ADDRESS] where you can fill it in online (please do *either* the paper or online version, not both).

Yours sincerely,

Elaine Cameron  
*Researcher at BCH and Aston University*

*Please note: This letter has been sent from Birmingham Children's Hospital on our behalf. We do not have access to your address or personal information. The Hospital is not responsible for the contents of this letter.*

### 3.4.2 Information sheet

#### Information about the study

**1. Who are we?**

We are a group of researchers who work at Birmingham Children's Hospital and Aston University. We do research on parents' views and decisions about children's health care.

**2. Why are we doing the study?**

To find out about parents' beliefs and experiences of attending children's hospital appointments. These might affect how parents make decisions about health care for their children, so it could help the hospital to design better services and support systems for families.

**3. Why have we asked you to take part?**

Because your child has a **General Paediatric hospital appointment** scheduled within the next two months. We hope that you'll be able to tell us how you think and feel about going to this appointment.

**4. What will you have to do if you take part?**

Just fill out the questionnaire and return it in the envelope provided, *or* complete it online at [WEB ADDRESS]. Remember to do only *one* of these, do not fill out both versions.

**5. What will happen to your answers?**

We will combine your answers with other parents' answers then look for the patterns in this 'data' using statistics. This will tell us how parents think about going to appointments. We will write about what we find in research reports which we will share with the hospital and other health science researchers. If you would like a copy of the findings just get in touch with us using the contact details on the front of this letter.

**6. Will anyone know if you've taken part?**

No, your answers will be **completely anonymous** and we will not be able to tell who you are. We will not share your answers with anyone who is not part of the research team. This means that the health care of you and your child will not be affected in any way if you take part in this research.

**7. Are there any benefits to taking part?**

There are no direct benefits to you for taking part, but your answers will help our research and help the hospital to support families who are coming for appointments. Also, as a thank you for helping us **we will donate £1 to a charity of your choice** when we receive your completed questionnaire.

**8. Do you have to take part?**

No, taking part in this study is completely up to you. By returning a completed questionnaire you will be agreeing for your answers to be included in our research. All of your answers will be completely anonymous.

**9. How can you ask questions or find out more?**

Just contact the main researcher Elaine Cameron on 07770 701 908 or at [e.l.cameron@bham.ac.uk](mailto:e.l.cameron@bham.ac.uk)

### 3.4.3 Instruction and further comment sheet

#### Going to General Paediatric Appointments Questionnaire

##### Instruction and Comment Sheet

This box answers some questions you might have about filling in the questionnaire.

**1. WHICH appointment is the questionnaire about?**

The questions are about your child's General Paediatric hospital appointment that is scheduled within the next two months. Please answer all questions with this appointment in mind unless it says otherwise.

**2. WHO should fill it in?**

A parent or caregiver of the child with this appointment who usually takes them to their health appointments.

**3. WHEN should you fill it in?**

Please fill in the questionnaire before your child's hospital appointment and return it as soon as you can.

**4. HOW should you fill it in?**

Please mark the boxes like this . If you change your mind just cross out your old answer and make your new choice.

**5. HOW LONG will it take?**

The questionnaire will take about twenty minutes to complete.

**6. What should you do if you have more than one child with a General Paediatric appointment?**

Please answer about the child with the appointment that is soonest.

**7. What should you do if your child has more than one health issue?**

Please answer about the health issue that the hospital appointment is for, even if it is not your child's main health issue. At question 28 on the questionnaire you can tell us more about your child's other health issues.

If you have any other comments about what you think of attending your child's hospital appointments, or about the questionnaire then please write them here and send this sheet back with your completed form.

#### **COMMENTS**