The paediatric journey to and through the emergency department: the parent's experience

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2022

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ACKNOWLEDGEMENTS

I would like to express my gratitude to my supervisor, Professor Tony Long, for his enduring patience, his scathing humour and his unquestioning support for the extended duration of this study. I do hope that I was not a contributing factor to his decision to retire after his prestigious career and the significant contribution that he has made to improving the quality of life for children and families. I wish him all the very best.

I would like to thank my colleagues for their support and for allowing me the time and opportunity to complete my research in our work place. In particular, I would like to thank my friend, Sharon, for continually nudging me forward.

I am more than grateful to my family and friends for their unswerving support for such a long time. To my late parents who were always encouraging and so proud of me. “YOU can do it. You can do anything you put your mind to!”

To my husband, Dave, who has given me space and who has patiently listened to me, constructively engaging with my work and helping me to see the trees in the wood. To my precious children, Sam, Matthew and Hannah, who have been patient and understanding throughout. I am looking forward to seeing how much you have all grown.

ABBREVIATIONS

A&E	Accident and emergency (department)
APNP	Advanced paediatric nurse practitioner
BNI	British Nursing Index
CASP	Critical Appraisal Skills Programme
CINAHL	Cumulative Index to Nursing and Allied Health
ED	Emergency department
GDPR	General Data Protection Regulation
GP	General practitioner
HCP	Health care professional
HES	Hospital Episode Statistics
HRA	Health Research Authority
IRAS	Integrated Research Application System
NHS	National Health Service
PICO	Patient/Intervention/Comparison/Outcome
POAU	Paediatric observation and assessment unit
PPI	Patient and public involvement
PRISMA	Preferred Reporting Items for Systematic Reviews Meta-Analysis
RCEM	Royal College of Emergency Medicine
RCPCH	Royal College of Paediatrics and Child Health
RCN	Royal College of Nursing
RCT	Randomised control trial
UTC	Urgent treatment Centre
WIC	Walk-in centre

ABSTRACT

Parenthood will inevitably include caring for a child suffering from a mild to moderate illness requiring access to health care. Most childhood illnesses can be managed in the community, and a variety of primary care services are available with patients being encouraged to attend the one most suitable for their needs. Yet the number of children visiting the emergency department with non-urgent illness continues to rise annually, with paediatric attendance representing over 25% of the total workload.

This study investigated why parents chose to bring their child to the emergency department and explored the journey through parents experiences when making this decision. The research question was 'What are the concerns, expectations and experiences of parents who choose to bring their child to the emergency department with mild or moderate acute illness?'

Parents of children aged 0-16 years presenting with non-urgent conditions were approached over an 18-month period to participate. Prior to discharge, focused interviews were used to explore the antecedent decision-making factors leading up to attendance and parents experience of urgent care were explored.

Parents often experience complex journeys prior to attending the emergency department following multiple health care contacts and referrals from other providers. The findings challenge assumptions that have led to the criticism of parents for overuse of the health service and, instead, highlight the culpability of health care professionals and health systems in generating increased demand for urgent care.

For most parents, attending the emergency department was a considered decision. Interaction with professionals had a significant effect on their experience. Health care professionals were powerful agents controlling resources and knowledge, but they were influenced by pressures and targets within the health service. The NHS is a complicated system that parents tried to navigate, but they were thwarted by its complexity and conflicting messages. When their child was unwell parents wanted a service that was simple to access, and that would offer a standard of care that would reassure and empower them to continue to care for their child.

COVID IMPACT STATEMENT

The original design of the study was to obtain a sample size of 50 parents of children brought to the emergency department with mild acute illness. The onset of the COVID pandemic and the subsequent restrictions imposed led to a drastic reduction in attendance by children at emergency departments throughout the UK meant that recruitment had to be curtailed at 35.

A planned follow up telephone call two days after the emergency department attendance was removed from the data collection process following the onset of the COVID-19 pandemic. It was not considered appropriate or necessary for the researcher to attend the hospital solely for the purpose of completing telephone interviews. This was intended to explore the experience of parents after allowing for period of reflection following their visit. Instead, the gathered data relied on parents' present and past experiences of their exposure to the health care services.

It was projected that the data would be collected over a period of three months but was eventually extended to 18 months until the desired maximum variability of the sample was achieved and time became limited by the impending completion date of the doctoral study.

It was anticipated that the study might detect any differences in maternal and paternal driving factors which led parents to take their child to the emergency department. However, the onset of the COVID-19 pandemic part way through data collection forced restrictions on the number of people thought safe to be in the department, allowing only one parent to attend with their child during the hospital visit. This limited to the ability to comment on this element of children's attendance at the emergency department.

Therefore both recruitment and data collection activities were adversely affected by the pandemic.

CHAPTER 1

INTRODUCTION AND OVERVIEW OF THE STUDY

This thesis is a report of a study that explored psychosocial influences on parents' decisions to bring their child to the emergency department with a mild to moderate illness that could have been managed in a primary care setting. Non-urgent paediatric attendance at emergency departments continues to rise annually with health professionals' perception of causal factors differing significantly from those of parents. Despite the introduction of alternative primary care services and government efforts to encourage patients to choose the right health service for their needs, there remains an apparent mismatch of service delivery and service demand. When services are utilised 'inappropriately', attitudes of health staff can result in patients, and in particular parents of unwell children, feeling criticised and disempowered (Neill & Coyne, 2018).

There is growing interest in the motivational drivers behind paediatric emergency department attendance. This has not yet been fully captured as research undertaken so far has taken a prospective or retrospective approach that considers what action parents might take, or what action they have taken after a period of cooling down and reflection. Many studies about children's attendance to the emergency department have adopted a quantitative questionnaire approach, yet we are advised to explore service need and provision by listening to the perspective of the parent (Kennedy, 2010).

There is an identified gap in research that employs a qualitative listening approach to the parents' experience and that captures the urgent drivers behind their attendance when they are present in the emergency department.

This study investigated the various antecedent factors that led to the decisions made at the point of need that steered parents to the emergency department. It explored the parents anticipated outcome of the visit and their experience of seeking help for their child when they were unwell.

The purpose of this study was to contribute to the debate over the increasing demand for paediatric emergency care. From the study findings, a service model designed to meet the changing needs of families is proposed.

1.1 THE PROBLEM

Parenthood will inevitably include caring for a child suffering from a mild to moderate acute illness who may present with such symptoms as fever, cough, vomiting, or a non-descript rash. The pattern of common childhood illness can be difficult to predict with children deteriorating and recovering equally rapidly. Naturally, caring for a sick child can create high levels of anxiety for parents who worry that their child might be suffering from a serious or life-threatening illness such as meningitis or sepsis. Parents are often quick to seek medical advice and treatment, and, fortunately, most of the time they can be reassured that their child has no serious illness and should recover with minimal intervention.

A problem for parents is which service to select to access the sought-for medical advice. Research has shown that parents prefer to see their GP (Gnani et al., 2016) but will report difficulties in obtaining same-day appointments. Successive governments have been keen to divert non-urgent patients away from their local emergency department by encouraging the use of alternative services such as minor injury units, walk-in centres, NHS helplines, and pharmacies. Yet for parents, this has caused the boundaries of service provision to become blurred and confusing when, at moments of high anxiety, they seek to establish which provider will be most suitable for their child's health needs. The emergency department often becomes the simplest option.

1.2 IMPLICATIONS OF THE PROBLEM

1.2.1 Financial Implications

Attendance across all emergency departments is rising annually and placing the NHS under continued and unsustainable financial pressure. A report by NHS Digital (2018) showed that in 2017-18, a total of 23.8 million patients attended an emergency department, an increase of 2% compared with 2016-17. More recent data is less reflective of the rising trend after the COVID pandemic saw a temporary reduction in the numbers attending the emergency department. However, as COVID restrictions eased, attendance began to increase again and by summer of 2021, attendances to the emergency department had risen above their pre-pandemic peak. In the quarter ending August 2021, attendances were 3.3% higher than the same period in 2019 (Barker, 2022).

Specifically, there has been a sharp rise in paediatric attendance to the emergency department following the pandemic, with comparative figures for children attending departments in four UK major children’s hospitals showing an increase of 48%, from 15,954 in 2018, to 23,661 in 2021 (RCEM, 2021a).

Children represent 25-30% of all UK accident and emergency attendances (RCPCH, 2018a), and a substantial portion attend for non-urgent illness or injury considered manageable within the primary care setting (Simpson et al., 2021; Williams et al., 2009). Attending the emergency department is a costlier option to visiting a GP. The average cost of a GP appointment is £39 compared to the average cost of a visit to the emergency department of £359 if treatments and investigations are performed (The Kings Fund, 2022). The financial cost of emergency care to the NHS has increased significantly from £2.3 billion in 2013/14 to £3.5 billion in 2019/20 (NHS Digital, 2021). If this trend continues, the cost and demands on the health service will continue to rise to untenable levels.

1.2.2 Quality of Care

The rising numbers of patients and the associated rise in financial costs affect the availability and quality of emergency care (NHS England, 2019). Healthcare staff are required to do more to meet demand with already stretched resources. The diluting of services result in care efforts being distracted away from the more unwell child with a genuine need for urgent treatment, by the volume of non-urgent presentations filling the emergency department. The increasing waiting times and subsequent failure to meet the prescribed four-hour target for total length of stay in the emergency department leave healthcare staff feeling pressured to treat the less urgent patient before they breach the government’s waiting time threshold (Henderson, 2022). Alternatively, children are admitted to inpatient beds who may actually be fit for discharge home within a short period of time, for example if they are waiting for the results of investigations (Keeble & Kossorova, 2017).

1.2.3 Environment: Overcrowding

For a number of years, The Royal College of Paediatrics and Child Health (RCPCH) has driven standards for paediatric urgent care, specifying that emergency departments receiving children should have a dedicated children’s area that is child- and family-focused and staffed by healthcare professionals (HCPs) with expertise in paediatric care. Arguably, the successful implementation of the standards has contributed to the rising number of attendances. It is understandable that parents will have more confidence in bringing their child to a dedicated family-friendly environment to be examined by paediatric specialists (Holden et al., 2017). Standards produced by the RCPCH (2018a) advocate the allocation of one bed space or cubicle per 5000 annual child attendance. While NHS Trusts have sought to meet the standards, often confined by the limited space available in an established emergency department, the rising attendance is overwhelming small departments. The number and percentage of all patients spending over four hours in the emergency department has correspondingly risen in recent years. In April of 2022, this figure was 28% (The Kings Fund, 2022). The effect of an overcrowded environment, which is intended to be child and family focused, exacerbates an already stressful situation for anxious families. There are resulting delays in treatments, pain management, longer wait times, and a negative impact on patient dignity and privacy (Unwin et al., 2016).

Nursing staff will often report that an area feels unsafe due to lack of capacity as sick children are placed in the waiting room pending the availability of a bed. There is evidence to suggest overcrowding contributes to a reduction in care quality, delays in commencing treatments and reduced compliance with guidelines as staff attempt to prioritise the overwhelming number of patients in their care (Jarvis, 2016).

1.3 STAFF STRESS AND ATTITUDE TOWARDS PARENTS: INAPPROPRIATE AND NON-URGENT ATTENDANCE AT THE EMERGENCY DEPARTMENT

In response to increasing workloads, staff can experience emotional exhaustion, stress and even burnout (Paparella, 2015). Patients want prompt, kind and compassionate care, however the impact of a rising patient to nurse ratio is poorer communication and relational care (Bridges et al., 2019). Personal observation from working in an emergency department confirm the effect on the clinical staff whose workload is often overwhelmed by the volume of patients attending with low acuity illness. Often the triage nurse will imply criticism of the parent’s decision to bring the child to as they handover “this child does not need to be here”.

Indeed ‘inappropriate attendance’ is a term that health professionals have often given to patients attending the emergency department with apparent non-urgent problems deemed manageable in a primary care setting. The use of the term is subjective and often applied in a retrospective manner after a clinical diagnosis is made. It has become a historical debate, a problem that has been recognised for many years without having an impact on rising demand. Research around 'inappropriate attendance' dates back to the 1950s and found enormous variability with 10% - 90% of patients considered to be manageable outside the hospital setting (Murphy, 1998). Prince et al. (1992) carried out a study that asked doctors to review children's emergency department attendance records retrospectively; over 30% were considered 'inappropriate'. More recent findings however considered that 60% of children who attend emergency department could be self-managed at home (Watson & Blair, 2018).

Professionals focus on parental lack of knowledge when considering the appropriateness of paediatric attendance (Butun & Hemingway, 2018; Conlon et al., 2021; Patton & Thakore, 2012). There is frustration at the perceived failure of the parent to recognise that a child is suffering from a mild illness only, and an expectation that the parent should manage the illness without intervention from the emergency department. A historic review of staff attitudes found 'blaming the patient' for 'inappropriate attendance' and highlighted the impact on care delivery towards such patients, with clinicians often exhibiting less sympathy and understanding and more irritation and frustration (Sanders, 2001). There were no further studies found to suggest that this may have changed.

In recent years, the literature has sensitively moved away from the term 'inappropriate attendance' and has explored 'why patients present to the emergency facility with non-urgent conditions', yet the implications are the same. A judgement is made that the patient or parent should not have chosen to present to the emergency department when the patient's condition is not deemed an emergency by the health professional.

It is evident that qualified health professionals are placing the onus on the unqualified parent to know when and where to seek medical help. Attitudes of staff can, then, convey criticism for seeking urgent medical attention for a minor childhood illness, with parents made to feel silly or stupid (Neill & Coyne, 2018).

Parents who fail to receive the reassurance that they seek may sense lack of acknowledgement or indifference to their worry or emotional distress. In contrast, positive communication between staff and parents, which includes empathy, respect for beliefs and concerns, and providing clear information will promote parental confidence both in the clinician and in their own ability to care for their sick child.

1.4 PARENTAL ANXIETY: CARING FOR A SICK CHILD AND MEDIA INFLUENCE

Over recent decades, child mortality rates have declined, and overall population health has improved across the UK. Life threatening illnesses are at an all-time low, yet the fear over the potential loss of a child has intensified (Conlon et al. 2021; Gill et al., 2013; Rowe et al., 2015).

Media campaigns to raise awareness of meningitis and sepsis have inadvertently increased parental anxiety around caring for children with a minor illness as the symptoms for serious bacterial illness are emphasised as vague and non-specific (Kai, 1996; Neill et al., 2014; Watson & Blair, 2018). The media further serves to increase public alarm when there are headlines that feature the rare and unfortunate instances of a child developing a fever and dying within a few hours of becoming unwell.

Parents are particularly concerned about fever followed by breathing problems, rashes, pain, vomiting and if the child differs from their ‘normal self’. Parental concern is greater when the child is younger as these children are seen as being most vulnerable with a higher risk of rapid deterioration (Carter et al. 2020; Halls et al., 2017; Woolfenden et al., 2000). Parents want to do the right thing for their child and their ability to assess the severity of illness is often obscured by high levels of emotion and anxiety when their child is sick (Neil et al., 2014; Rowe et al., 2015).

The Internet has become the first choice for information for parents when their child is unwell (Neill et al., 2014). Online health advice is instant, seems current and easy to access but the quality of unregulated health information is questionable. Parents can feel overwhelmed with conflicting advice, which rather than offer reassurance, evokes further concern over the potential severity of their child’s illness (Walsh et al., 2015). Advice is often sought from fellow parents via online social groups who offer a mixture of interpretations of symptoms and possible diagnoses based on their own experience and that of people they know. The potential seriousness of the illness is emphasised, and parents encourage one another to seek professional help (Bryan et al., 2020; Doyle, 2013).

The mounting threat of a serious illness and lack of confidence in their ability to care for their sick child generates an unwillingness to tolerate uncertainty. Parents are reluctant to take risks and watch and wait. The increasing worry becomes a serious driver for urgent reassurance and parents have previously described a sense of relief when arriving in emergency department (Butun & Hemingway, 2018; Gill et al., 2013; Rowe et al., 2015).

The reassurances parents seek include having their concerns taken seriously, a thorough examination of their child, a clear explanation of the illness and advice on how to care for their child whilst they are unwell. If parents feel their concerns are dismissed, do not have confidence in their child’s assessment, or they are not given information and advice on how to manage the illness, they will make multiple contacts with health professionals until they feel they have received the reassurance, answers and the best care for their child (O’Cathain et al. 2019; Ogilvie et al., 2016; Woolfenden et al., 2000).

The emergency department is often the preferred option for its simple access and 24-hour availability, the perceived expertise of the HCP and the availability of rapid diagnostic testing (Holden et al., 2017).

1.5 PROFESSIONAL ANXIETY: CARING FOR A SICK CHILD AND MEETING EXPECTATIONS

While parental worry over minor illness is identified as a challenging factor in the battle over rising emergency department attendance, parental worry is paradoxically a consideration for identifying possible sepsis.

The sepsis-screening tool developed by The UK Sepsis Trust (2019) and guidance from the National Institute for Health and Care Excellence (2016) have lowered the threshold for suspecting sepsis. Since symptoms in children may be non-specific, they advise that clinical suspicion should be high and investigations initiated in the presence of significant parental worry, fever, or any other changes to clinical observations. This generates cautious patient management as HCPs share an equal anxiety with the parents over ‘missing something’ (Canares et al., 2014, Turbitt & Freed, 2016). Professional anxiety is exacerbated by recent high-profile media coverage focusing on failures to implement paediatric sepsis guidance and possible avoidance of child deaths.

Furthermore, fear of criticism from peers or patients, complaints to the hospital or the professional regulating body, litigation and vilification by the press is driving forward defensive practice (O'Dowd, 2015). HCPs who previously may have identified a patients attendance as inappropriate are forced to cautiously initiate investigations and treat minor illness as potential symptoms of a more serious infection. Investigations will support the clinical decision to do nothing, offer reassurance to the parent and will positively reinforce help seeking behaviour and the appropriateness of the attendance.

Professional anxiety around caring for children is likewise evident in primary care services. There are higher levels of concern for younger children and an increased likelihood of referral into secondary care (Canares et al., 2014; Cecil et al., 2015). Studies have found that around 50% of parents received advice to attend emergency department from another HCP, suggesting a reluctance to manage acute health problems and any potential risk (Mason et al., 2017; Williams et al., 2009). This is possibly due to a lack of paediatric expertise and confidence. The changes in organisation and variety of urgent care options may well have diluted a clinicians competence and experience of treating a sick child.

On arrival at the emergency department, children are often examined by less experienced junior doctors who are under pressure from the four-hour breach targets, rising demand and effects of overcrowding, and to make rapid decisions on patient management. There is further pressure to respond to parental anxiety and expectations by over investigating, over treating, and having a lower threshold for admission (Neill et al., 2018). One study explored the changes over a ten-year period for most prevalent conditions diagnosed in children on admission to hospital. In 2006/7, the most commonly diagnosed condition was abdominal pain with a total of 59,966, whereas in 2015/16, the highest number of children (91,386) were admitted for a viral infection (Keeble & Kossorova, 2017). As a result, there is an associated rise in hospital admissions for children with minor illness who are subsequently discharged home a few hours later as the inexperienced clinician responds to departmental pressures and adopts a minimum risk approach (Gill et al., 2013; Irwin et al., 2015; Saxena et al., 2009). Attendance at the emergency department, diagnostic investigations and admission to hospital are proving very expensive management options for children with a mild acute illness (Gill et al., 2013). Professional anxiety and cautious management are reinforcing parental anxiety and help-seeking behaviour.

1.6 GOVERNMENT RESPONSE TO THE INCREASING DEMAND FOR CHILDREN’S URGENT CARE

Children represent 25% of emergency department attendance and 30% of the GP workload yet there have been limited initiatives to raise standards for children’s services over the years (Viner et al., 2018). In 2004, the National Service Framework for Children, Young People and Maternity Services was published by the Department of Health, setting out child health standards for first time. It recognised that children are frequent users of urgent and emergency care with mild acute illness, that services provided should take account of the special needs of children and families, and access to a primary health care professional made available within 24 hours. While it refers to the availability of alternative ‘out of hours’ provision, it was progressive in suggesting co-locating services for children who are ill or injured with appropriate cover for urgent care at all times (Department of Health, 2004).

It is doubtful the standards were implemented as intended, since a review of children’s services in 2010 by Sir Ian Kennedy criticised health policy and practice. He pointed out the health care services are generally influenced by adult care with child health considered a lesser priority. The review expressed concern that parents of acutely sick children are expected to navigate the range and complexity of NHS services available to find the right option. Kennedy supported the National Service Framework for Children, Young People and Maternity Services in recommending a single point of access to urgent care services for children and young people (Kennedy, 2010). Indeed, a configuration to co-locate urgent care services is supported by an increasing number of professional bodies (RCEM, 2015).

Instead, service design has continued to focus on the health needs of adults, with children absorbed somewhere into the system. Despite the many recommendations for children's service improvements over preceding years (Kossarova et al., 2016), most are yet to be implemented. The most recent service model, The NHS Long Term Plan, recognises the problematic rise in paediatric emergency department attendance but hands responsibility to local areas to design and implement their own integrated models of care (NHS England, 2019).

A report by the Nuffield Trust presented various models of children's services that have emerged around the UK. These included a greater collaboration between primary and secondary care with joint care pathways and paediatric support in the community, information tools to aid parental decision making, GP referrals to an Advanced Nurse Practitioner rather referrals to secondary care, and a children's walk-in centre (Kossarova et al., 2016). These demonstrated varying levels of improvement to the quality of care for children and families. They do not provide consistency and clarity to worried parents making a decision on which service to access with their acutely unwell child.

As a result, there remains a disparity between a health service that is designed around the expectations of the provider, and a health service designed to meet the expectations of families seeking care for their sick child.

1.7 THE RESEARCHER'S ENGAGEMENT WITH THE PROBLEM

My professional role is Advanced Paediatric Nurse Practitioner (APNP) working clinically within the paediatric area of a district general hospital emergency department. I autonomously assess children aged 0-16 years; this includes the physical examination, relevant investigations, medical prescribing and formulation of diagnosis before making the decision to discharge home with information and advice, or admit to the inpatient services.

The APNP role was commissioned in 2006 by what was previously the Primary Care Trust and is now the Clinical Commissioning Group, to maintain a consistent paediatric presence in the department. The intention was to prevent inappropriate and costly admissions to the inpatient facility, and to discourage attendance to the emergency department by improving health literacy, providing education, information and signposting. This has achieved some degree of success with fewer inpatient admissions by the APNP. Reflecting the national trend however, paediatric attendance to the emergency department continues to rise.

During my time working in the emergency department, I have observed a notable difference in thresholds that might signify an unwell child to a HCP to those of the parent. For example, triage documentation, completed by a nurse shortly after arriving in the emergency department, will detail the presenting complaint and often state parental concern as the child is “not their usual self” but conclude with the “child is happy, alert and eating crisp at triage”. There is an implied criticism parents are inappropriately worried, and the child did not need to attend the emergency department.

I have equally gained personal insight from parents into the reasons why they choose to seek urgent medical care for their mildly to moderately unwell child, which can range from seeking reassurance and wanting their child to be ‘checked out’, to concern that their child is extremely unwell because they have a fever. Many parents contact alternative services, only to be advised to attend the emergency department anyway and will often report a frustrating journey through the various systems. Parents will express a lack of confidence in primary care assessments, feeling that their concerns were dismissed or that their child was not examined thoroughly. They will continue to access multiple health providers until they are satisfied that their child is receiving what they perceive is the most appropriate and expert care.

The variance in the perception of healthcare between the provider and the recipient generates personal feelings of protectiveness and defence of this client group. Fundamental to the APNP role is family and child centred care alongside the desire to ensure an accessible quality service. Supporting and empowering parents to care for their sick child at home and alleviating parental anxiety, often achieved just by giving information and reassurance only, is considered highly valuable to both the family and practitioner. While this sounds a simple outcome, it appears difficult to achieve in the present system of healthcare.

This doctorate study permitted credible explorative research into the parents journey from the events preceding the attendance to the emergency department and their experience of their healthcare encounter. From the findings, it proceeded to question if the parents attendance with their mild to moderately unwell child deserved to be labelled ‘inappropriate’.

I began this journey in 2012 when there was little insight into the decision-making process behind the parental choice to attend. Since then, new studies have been published that have explored the phenomenon, yet none have undertaken a contemporaneous interview while parents were attending the emergency department to capture the immediate drivers behind the decision to attend, before parents had an opportunity to later reflect on their decision.

1.8 SUMMARY

Children become unwell with mild acute illness that generates disproportionate levels of parental anxiety leading to urgent help seeking behaviour. There are multiple services that have become available however these have been shown to cause confusion and parents continue to present their children to the emergency department, contributing to the significant rise in attendance. Health care professionals are sharing higher levels of anxiety, frightened of mistaking a mild illness for early signs of a serious bacterial illness. Guided by sepsis policy, children are over investigated (Bradford-Duarte et al., 2019), which serves to reinforce parental anxiety and help seeking behaviour. Government has been influenced by adult demand with little specific guidance to paediatric urgent care despite the significant percentage of children who utilise services. Various models of care have achieved some success; however, these are not national interventions and knowledge of what services are available locally and the scope of its provision is vital for parents for their success.

My own role working within the emergency department of a district general hospital is perfectly placed to explore if families are currently failed by a service that expects them to respond to the organisation, rather than a service organised and responsive to their needs. The study was designed to gain insight from partnering with parents to explore their experiences, what they need and hope for when seeking health care for their unwell child. Ultimately, the aim was to inform service modifications to paediatric urgent care designed to meet the needs of the family regardless of the medically focussed level of illness.

1.9 STRUCTURE OF THE THESIS

The thesis is structured in seven chapters.

Chapter Two presents a focused systematic literature review of knowledge and insight into paediatric utilisation of urgent and emergency care. It explores factors in parental decision-making, parental expectations and experience of seeking urgent care when their child is unwell. It reinforces gaps in knowledge that serve to influence the purpose of this study.

Chapter Three describes the design of this study, defending the methods chosen, all aspects of sampling, data collection and analysis, efforts to enhance rigour and ethical consideration.

Chapter Four presents the findings from the data using thematic analysis of semi-structured interviews. The data elicited from 35 interviews were considered sufficient to generate enough evidence to answer the research question. It identifies seven distinctive themes that captured the experience of parents seeking help for their unwell child.

Chapter Five forms the discussion of the findings by using Giddens theory of structuration to explore the social interactions that influenced parents help seeking actions. It considers the actions of parents and HCPs working within the rules of the structure of the NHS. It highlights the capacity for agency and the ability to modify the rules of the structure to redress the power imbalance between the HCP and the parent. It proceeds to make suggestions for changes and proposes a new model of urgent care for paediatric services.

Chapter Six concludes the study with key messages from the research findings and suggestions for future study.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of the literature review is to identify key evidenced based studies in the area of interest and synthesise and critically evaluate what has already been found. It proceeds to identify a gap in the literature that can be addressed by the research question (Grant & Booth, 2009). The review begins with a search of accredited paper and electronic sources, using a clear systematic plan with justifiable search terms defining what will be included or excluded from the search (Hart, 2018). Once studies are identified, they are evaluated for quality and evidence (Smith & Noble, 2016). The intention of this literature review was to establish what relevant evidence existed already and where there was a gap in the evidence base (which this study was designed to address). It was expected that new perspectives would be gained on the relationship between the selected problem and current practices.

The literature review was formally undertaken at the beginning of the study with a full update in 2019. Further updating was intermittent during the COVID-19 pandemic as researchers and publishers focused on that. A final update was undertaken as the thesis was finalised, and this is reflected in the discussion chapter.

2.2 THE SEARCH QUESTION

The search process begins by reframing the topic of research into a well-structured searchable question. This is fundamental to retrieving literature that is relevant to the study and answers the question. A number of frameworks have been developed, the first by Richardson et al. (1995) who devised PICO, a mnemonic for Patient/problem, Intervention, Comparison and Outcome that was designed to develop a well-built question from these four components. This is helpful when developing clinical questions, however further frameworks have evolved to address the variety of research and disciplines. The SPICE model was formulated to assist practitioners in identifying practice-based questions (Booth, 2006).

S – Setting: the context for the question.
P – Perspective: the users, potential users, or stakeholders of the service.
I – Intervention: what is offered to the users?
C – Comparison: are there alternatives?
E – Evaluation: what is the result?

Table 1 below demonstrates the formulation of the research question utilising this framework.

Table 1: SPICE Framework

S	Setting (context)	Caring for a child with mild to moderate illness
P	Perspective – for whom?	Parental concerns and expectations
I	Intervention – what?	Choosing to bring their child to the emergency department
C	Comparison – compared with what?	Rejected alternative urgent care service provision.
E	Evaluation – with what result?	Experiences of urgent care and comparison with prior expectations

The following research question was generated.

What are the concerns, expectations and experiences of parents who bring their child to the emergency department with mild or moderate acute illness?

Search terms were expanded to encompass synonyms, alternative spelling and truncation. Keywords from previous articles on the same topic were included, for example ‘inappropriate attendance’.

Table 2: Search terms

S	Setting – where?	• Non-urgent, mild/moderate, unnecessary, inappropriate • unwell, ill, fever*, sick • infant, child*, paed*, p*ediatric
P	Perspective – for whom?	• Parents, carer, famil* mother, father, of a child* with illness • Concern, influence, anxious, worry, expect*
I	Intervention – what?	Emergency department, Accident and Emergency, A&E, urgent care, inappropriate attendance
C	Comparison – compared with what?	Alternative sources of support that had been rejected (GP, pharmacy, helpline)
E	Evaluation – with what result?	Experience matched to expectation

2.3 SEARCH STRATEGY

Evidence from research continues to accumulate and is widely accessible via the Internet, yet searching for the best evidence can still be problematic. For example, Google Scholar is a freely accessible and easy to use search engine. It includes up to date, peer-reviewed online academic journals but has been criticised for not vetting the quality of all the journals in its index (Zientek et al., 2018). By comparison, bibliographic databases provide subject specific information that has been validated through an editorial process for accuracy and credibility and is subsequently considered more reliable for academic level research. However, the proliferation of databases, each with its own search protocol can be daunting and difficult to navigate around with many databases demanding a subscription to enable access (Greenhalgh, 2014).

As new information in health care is responsible for influencing and informing patient care, high quality evidence to support practice is essential. To generate an effective search for trustworthy and evidence based answers, a systematic exploration of all relevant resources is necessary. A search of online bibliographical databases specific to health related subjects and accessible was undertaken. These comprised of the British Nursing Index (BNI), and CINAHL (Cumulative Index to Nursing and Allied Health), accessing literature relevant to nursing and allied health professionals, students, educators and researchers. MEDLINE expands to include information for medicine and the Cochrane library was included for its ability to seek out the 'highest quality' research evidence from systematic reviews and meta-analysis. Google Scholar was included and sources screened for quality.

Key words and synonyms generated by the question were entered into the databases (see Table 2). For example, paediatric, child, infant, and the use of the Boolean operator 'and' to connect the search term with key words 'accident and emergency', emergency department and 'A&E'. Search terms were also combined to ensure completeness. Truncation was used for child* and p*ediatric to account for various spelling but did not yield any additional results. Once a key study was located, a search for similar results using SmartText, available on CINAHL and MEDLINE, was successful in finding further relevant studies.

The bibliographies for each study identified by the search were later scrutinised for further key references.

2.4 INCLUSION/EXCLUSION CRITERIA

The initial search was limited to papers published from 2005 onwards. This was to allow for papers assessing the impact of primary care policy reforms implemented in 2004. The reforms reduced patient access to ‘out of hours’ primary care services and are associated with increased emergency department visits for primary care sensitive conditions (Cecil et al., 2015). A number of historic papers, cited by further key studies, were included for their continued relevance to parental concerns and experience.

The search terms were limited to keywords contained within the title or abstract, and papers published in English. Only peer-reviewed publications were included since peer review considers the use of appropriate research methods and the significance of the paper’s contribution to what is already known prior to publication (Ware, 2013). Quantitative, qualitative and mixed method studies were included to reflect a comprehensive representation of paediatric attendance at the emergency department from a parental perspective.

Exclusion criteria were non-research or opinion papers, adult-focused studies, and studies that were chronic condition-specific such as asthma or epilepsy since these were focussed upon specialised healthcare provision. Studies that did not refer to parents and focused only on professional opinion, or which applied a retrospective review of case notes before formulating an opinion on the appropriateness of attendance were excluded. Some studies reported a lack of knowledge of alternative care provision as the main finding for reasons attending emergency department for non-urgent illnesses, however these studies were not based in the UK and had non-comparable models of healthcare (Benahmed et al., 2012; Stockwell et al., 2010)**.**

The original search revealed a plethora of papers discussing the increase in demand for paediatric urgent care and demonstrating the interest and importance of the subject matter. There are many published international studies, proving this is a global problem. As the search was narrowed, 271 studies were subsequently screened. Duplicates and non-research papers were removed, along with adult focused studies on attendance to the emergency department with non-urgent conditions. A further 13 studies were excluded as they referred specifically to emergency admissions to short stay units rather than attendance to the emergency department. (See Figure 1 “PRISMA flow diagram” below)

In total, 18 studies met the criteria for inclusion in the literature review. Within these, the number of studies investigating specifically parental concern numbered 13, and five studies explored the cause of rising paediatric attendance at the emergency department. One study looked at the perception of unnecessary use of emergency care for both adult and paediatric patients and was included for its reference to the concerns and decisions of parents when their child is unwell.

A number of studies considered the reasons for the rise in paediatric emergency department attendance. Studies undertaken in other countries were included for their similarity of findings to UK studies. The suggested reasons for the documented problems were separated into two themes, exploring the external factors and parental concern for their child.

Study designs included analysis of hospital-coded trends, retrospective review of case notes, questionnaires and interviews.

Table 3: Inclusion and exclusion criteria

Inclusion	**Exclusion**
• Publications from 2005 onwards • Papers published in English • Peer reviewed publications • Studies with keywords contained within the title or abstract • Quantitative, qualitative and mixed method studies • Studies that referred to mild, acute illness	• Adult-focused research • No full text available • Expert opinion, review articles and policies • No reference to parental perspective • Chronic condition specific: eg, asthma/epilepsy • Minor injuries • Reference to emergency admissions rather than attendance • Studies in countries with non-comparable healthcare systems to the UK

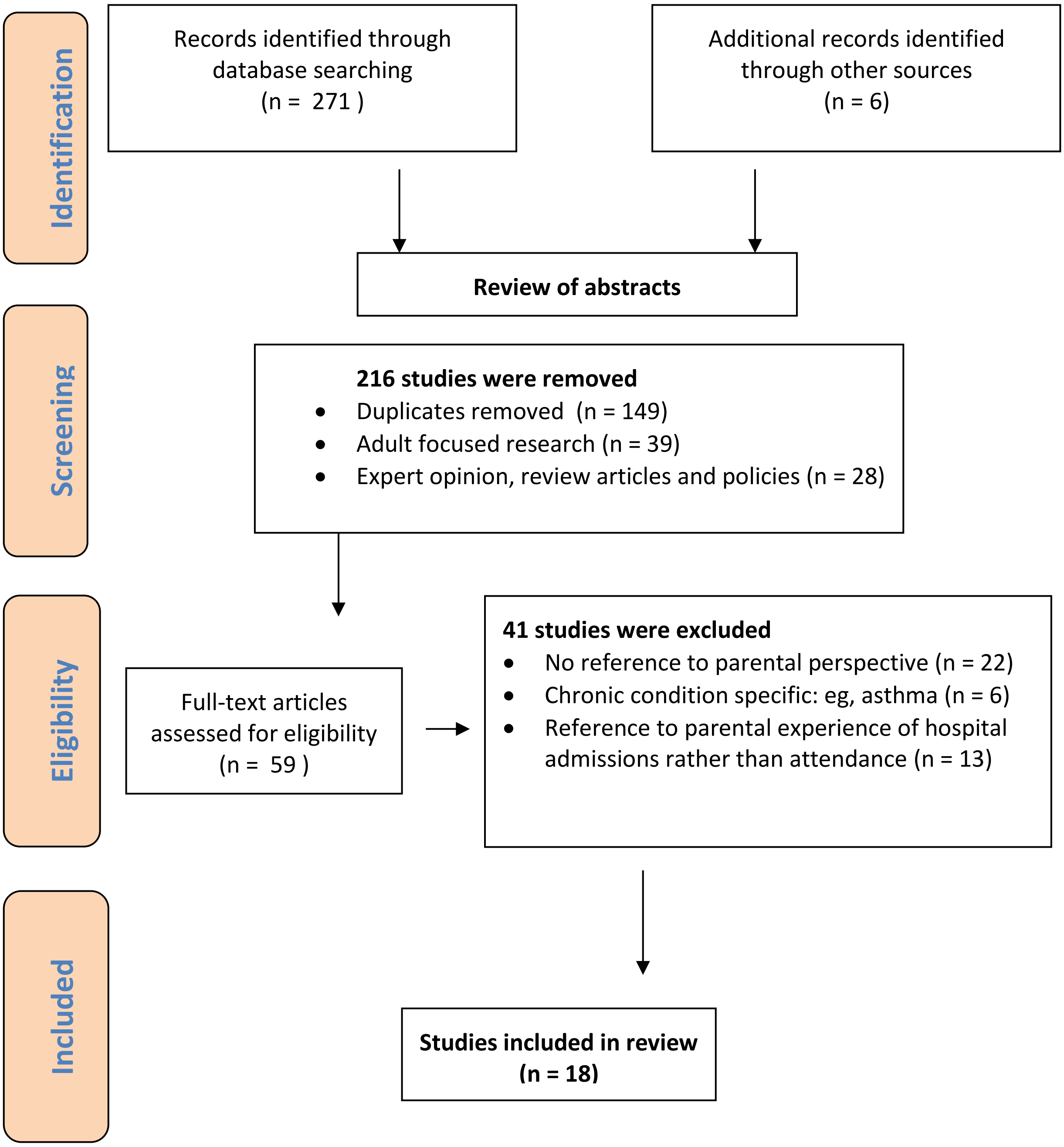


Figure 1. PRISMA Flow Diagram mapping the number of records identified, included and excluded, and the reasons for exclusions.

2.5 THE QUALITY OF THE EVIDENCE

The quality of published papers, even though registered in bibliographic databases, can vary with apparently significant and impactful findings limited by serious flaws in the methods selected or the conduct of the study (Greenhalgh, 2014). Methodological quality can be assessed systematically using a critical appraisal tool to identify validity and reliability of evidence relevant to the research question, and to evaluate how far results may be generalised or otherwise applied to inform patient care (Morrison, 2017). Conversely, there is an argument that critical appraisal checklists promote a mechanistic approach to evaluation and detract from thoughtful judgement of strengths and weaknesses the study (Greenhalgh 2014). Perhaps it is simply the case that appraisal tools can enable users of research evidence to adopt a systematic, structured approach to appraising the rigour of study while applying individual judgment to reach considered decisions about the worth of the findings.

A number of critical appraisal tools exist that are tailored to evaluate the study design. For example, the Joanna Briggs Institute offers 13 tools that appraise studies such as analytical cross sectional research, then move down the hierarchy of evidence to evaluate text and opinion (Joanna Briggs Institute, 2019). The Critical Appraisal Skills Programme (CASP) provides eight checklists specific to key study designs to assess research in three steps. Step 1 asks about the validity of the study and the presence of bias as this affects the classification and strength of evidence. Step 2 questions the certainly and clinical importance of the results. Step 3 considers the usefulness of the results and their relevance to the appraiser’s question. The CASP checklists were selected in this review for their coherent approach to evaluating the research papers. The tools are highly regarded yet simple to use, and they are specific to differing research designs (Hannes et al., 2010; Majid & Vanstone, 2018).

The design of the study can indicate the extent the research findings can be trusted; the commonly used hierarchy of evidence is widely accepted in evidence-based practice with the highest ranking study design assumed to be more robust (Evans, 2003; Greenhalgh, 2014).

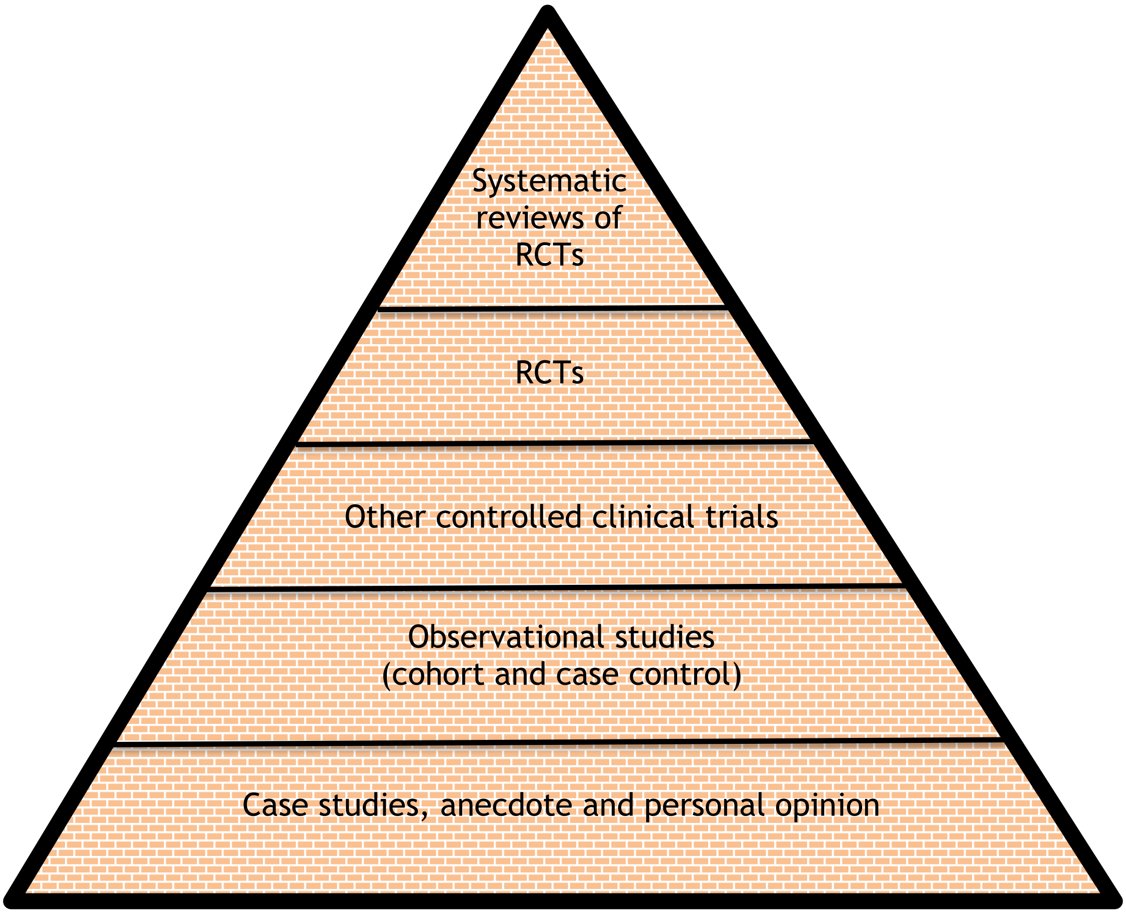


Figure 2. A simple hierarchy of evidence for assessing the quality of trial design in therapy studies (Greenhalgh, 2014)

Systematic reviews and meta-analysis are considered the highest standard of evidence for their rigorous and critical appraisal all the available scientific evidence (Cochrane, 2019). The prestige given to the researcher conducting a study placed at the top of the hierarchy make these types reviews highly desirable. Fewer obstacles, such as the requirement for ethical approval, can mean these types of studies are more easily produced resulting in a proliferation of less robust systematic reviews (Wormald & Evans, 2017). Indeed, the quality of available systematic reviews and meta-analysis remains vulnerable to presenting sub-optimal or misleading results by combining only retrospective or fragmented publications (Ioannidis, 2016).

Randomised controlled trials (RCTs) are thought to produce results that are at low risk of error or bias and provide evidence on the effectiveness of an intervention. This evidence is ranked at a lower level because the findings are based on a single population and factors specific to the study site such as resources, staffing levels or expertise can lead to strong assumptions, bias and limitations impacting on the findings of the RCT (Evans, 2003; Krauss, 2018).

As the hierarchy moves down the ranks, the weaker the evidence considered yet this is contested as concerns are raised about ranking of evidence when compared to its relevance to practice (Petticrew, 2003). For example a well-conducted observational study can provide richer evidence than a poorly designed RCT (Deaton & Cartwright, 2018). While quantitative methodologies dominate the hierarchy of evidence, the research question has to be addressed by the most appropriate study design and qualitative techniques such as interviewing are best employed to establish why people make decisions and choose a course of action (Petticrew, 2003).

This literature search located only one systematic review that comprised of just four studies, one of which referred to adult emergency department attendance, and none of the studies were undertaken in the UK. No RCTs were identified relevant to this literature review.

Five studies included in the review analysed statistical data pertaining to trends of attendance. All were undertaken retrospectively and generated large volumes of data. Four studies were based only on questionnaire data, whilst six studies employed a mixed methods approach using questionnaires and interviews. Two studies were conducted with qualitative interviews alone. Nine of these studies addressed parental concern specifically, four studies explored parental expectation and experience, and five studies explored the cause for rising paediatric attendance at the emergency department.

Three themes were identified from the most commonly reported issues: trends of attendance, reasons for presentation at the emergency department with non-urgent illness, and parental feelings about caring for a sick child.

Table 4: Table of Studies

Author(s) and date	**Title**	**Design**	**Findings/Results**	**Strengths**	**Limitations**
Butun & Hemmingway (2018)	A qualitative systematic review of the reasons for parental attendance at the emergency department with children presenting with minor illness.	Qualitative systematic review.	Themes identified: Dissatisfaction with primary care, perceived advantage of ED, child 'suffering', out of hours, reassurance, parental worry.	Identifies the expected features behind paediatric emergency department attendance.	Identifies problem of increasing attendance to UK hospitals yet explores 4 studies undertaken in the USA including one which was adult focused.
Costet Wong et al. (2015)	Why do parents bring their children to the emergency department? A systematic inventory of motives.	Questionnaire survey to establish an inventory of motives for attending ED.	Parental motives were goal orientated and emotion based. Parents would be unlikely to agree their attendance was inappropriate.	Large sample size of 497	Study was based in one children's hospital where parents are more likely to attend for the specialism.
Downing (2006)	A study of childhood attendance at emergency departments in the West Midlands region	Routine data on all new attendances by children under 16 years were available for 12 EDs in the West Midlands.	Injury related conditions increased with age. Respiratory and gastrointestinal were the most common medical conditions decreased with age. 11.5% of children were admitted to hospital.	Large study with high volume of data**.**	Data was collected from 12 hospitals including Children's hospital and findings were variable across sites.
Gill et al. (2013)	Increase in emergency admissions to hospital for children aged under 15 in England, 1999 – 2010	Population based study of hospital admission rates for children, based on Hospital Episode Statistics (HES)	Increase in emergency admission rates by 28% with a twofold increase of admissions lasting less than 1 day	High volume of data/trends.	Data was limited and unable to provide times or attendance or details of re-attendance.

Hendry et al. (2005)	Minor Injury and Illness: factors influencing attendance at a paediatric emergency department	Prospective questionnaire survey of 465 families selected by systematic sampling.	Parents view paediatric emergency department as an appropriate place to seek treatment for children with minor illness.	Comprehensive questionnaire survey eliciting unequivocal responses.	Omission of data from free text parental comments.
Holden et al. (2017)	Why do parents bring children with minor illness to emergency and urgent care departments?	Literature review and report of fieldwork in 2 UK hospitals.	5 main reasons for attendance: Parental worry Perceived advantages of ED Perception other services not suitable Social Network Influence Low confidence	Comprehensive and in-depth report on the behavioural aspects of decision-making.	Small sample size, only 8 parents were interviewed.
Kai (1996)	What worries parents when their preschool children are acutely ill, and why: a qualitative study.	Qualitative study using semi-structured one-to-one and group interviews. Sample size 95.	The symptoms that cause parents to worry and the fear of missing a serious illness.	Using a qualitative approach was able to provide insight into parental concerns and thinking.	One male GP researcher may have influenced parents' responses. Mainly mothers interviewed.
Keeble and Kossarova (2017)	Focus on: Emergency hospital care for children and young people.	HES Data analysis for 10 year period; Child attendances, admissions and diagnoses.	Rising paediatric attendance at ED, rise in admissions and change in most common diagnosis.	Long study over 10 years using data from NHS hospitals in England.	The quality of data collection and diagnosis coding can be variable.
Lai et al. (2011)	Paediatric Emergency Department Attendances between 2000 and 2009: Trends in a large UK Children's Hospital	ED attendance and admission data analysis over a 9 year period	27% increase in paediatric attendance at ED, 76% increase for medical presentations, 47% increase in admissions from ED.	High volume of data.	Does not explore if attendance and admissions were appropriate. Sample taken from one hospital only.

McGovern et al. (2017)	Parental Decisions regarding pre-hospital therapy and costing of the Emergency Department Visit	Cross sectional cohort study of 200 patients.	Attendances are often prompted by parental anxiety. Prior usage of emergency department is common.	Research took place at one hospital so results cannot be generalised.	Convenience sample during daytime hours, not reflecting any variation on night time attendances
McLauchlan et al. (2020)	Why do parents present to the PED with conditions suitable for the management in less acute settings?	Semi-structured interview.	Parents want care from the most appropriate service in unscheduled situations. Parents and HCP have low tolerance of risk.	Utilises questionnaires to establish demographic data and interviews to exploring the decision-making process.	168 questionnaires completed but only 13 parents took part in the subsequent interview.
Maguire et al. (2011)	Which urgent care services do febrile children use and why?	Case note review, telephone interview.	Parents prefer to access their GP. Identified a need for written advice on illness management.	Large sample size of 220 over 3 research sites.	Not all sample participated in all aspects of the study.
Neill et al. (2013)	The role of felt or enacted criticism in understanding parent's help seeking in acute childhood illness at home.	Glaserian grounded theory methodology, defined as 'the discovery of theory from data systematically obtained from social research'. Sample size 15 families.	Felt criticism teaches informal rules and expectations of how to behave. Parents want to appear as 'good' parents and experience anxiety around when to seek medical help.	Four sets of data collection over 6-year period.	Parents contacted the researcher should their child become unwell: possibility of bias when parents wanted to 'complain' about a negative experience
Rowe et al. (2015)	A&E: Studying parental decision making around non-urgent attendance among under 5s	Mixed-methods: Knowledge audit and qualitative interviews with parents	Parents are uncertain about choosing emergency department but this was overridden by the desire to act cautiously. emergency department is a simple service to understand and considered appropriate for their child's needs.	Clear objectives and findings. Three components to the research methodology; literature research and 8 expert interviews, interviews with parents, mapping of healthcare services in 5 locations.	Sample were recruited using 'free-find' recruitment and paid for participating. No access to emergency department triage records to confirm low category/mild acute illness.

Sands et al. (2011)	Medical Problems presenting to the paediatric emergency department: 10 years on	Quantitative Study: Retrospective review of electronic patient record and comparison with previous cohort.	An increase of paediatric emergency department medical attendance by 42%, with little change to the 10 most common medical presentations.	10 year comparative study	Only one research site, this was a Children's hospital and not representative of general hospital attendance. Changes in data collection methods.
Williams et al. (2009)	Making Choices: why parents present to the emergency department for non-urgent care	Quantitative Study: Prospective questionnaire based survey of 355 parents at Australian Children's Hospital	Parents engage in appropriate care-giving and care-seeking behaviours.	10% representative sample of annual attendance. High response rate of 97%	Did not provide information on how participants were recruited or when the questionnaire was completed.
Winskill et al. (2011)	Influenced on parents' decisions when determining whether their child is sick and what they do about it: a pilot study.	Mixed methods: Quantitative and qualitative questionnaire.	Parents recognise symptoms of sickness and attempt of seek the correct urgent care service prior to attending the ED.	Statistical analysis was undertaken on the quantitative data, themes were identified from the qualitative responses.	Pilot study, small sample size of 25 and inclusive of parents up to the age of 6 years old only. Results cannot be generalised.
Woolfenden et al. (2000)	Parental use of a paediatric emergency department as an ambulatory care service.	Mixed methods: Semi-structured in-depth interviews.	Parents use own triage to access the correct service. The perceived expertise of the children's hospital was a major factor in the use the Paediatric ED.	Appropriate methodology to base findings.	Small sample size of 25, based in one children's hospital.

2.6 CHANGING TRENDS IN PAEDIATRIC EMERGENCY ATTENDANCE

Whilst most of the literature focused on parental decision-making, five studies were included that explored the background to the rise and trends of paediatric emergency department use.

A retrospective review of electronic patient records for paediatric attendance to a UK emergency department over a one-year period was undertaken by Sands et al. (2011), and findings were compared to data from 10 years earlier. The study found the total paediatric attendance (both non-trauma and trauma) had increased by only 1% over ten years, (n = 39,394 vs 38,982) however there had been a huge shift in the proportion of children presenting with medical problems, with an increase of 42% (n = 14,724 vs 10,369). At that time, no changes in the presenting medical complaints that might account for the disproportionate increase were found by the study, and no substantive explanation was offered for the decrease in presentations for injury. However, methods of collecting data over the 10-year period were inconsistent; computer systems had changed, and data was dependent on both non-medical and medical staff gathering the information with resulting opportunity for confusion in the use of medical terminology. The authors remained confident that the data reflected national statistics on emergency department paediatric attendance. A slightly older study by Downing (2006) reported similar findings. Downing (2006) examined electronic data collected from 12 hospitals in one region, breaking down patterns of attendance by age range, and finding an increasingly high proportion of children aged 4 years or under attending with medical illness. The remainder of the data varied considerably between hospitals and failed to capture the urgency of presentations.

A study by Lai et al. (2011) similarly examined trends of attendance to the emergency department at a children’s hospital over a nine-year period (2000-2009). In contrast to Sands et al. (2006), it found an overall increase in paediatric attendance of 27% (n = 444,950) in this time period, with a profound increase of 76% of children presenting with illness. This is significantly greater than the findings of Sands et al. (2006) but may be explained by parent’s preference for a dedicated children’s hospital and the idea that a children’s hospital will provide higher quality care (Downing, 2006).

Lai et al. (2006) do not attempt to offer any explanation for the substantial rise in attendance, however Downing (2006) and Sands et al. (2011) suggest an inability to access GP and out of hours care, and improving standards in the emergency department meaning a child is seen and treated quickly, are proving a more attractive option for parents and thereby increasing attendance. Furthermore, heightened parental anxiety and the meningitis awareness campaign is leading to parents seeking medical help early, an increase perhaps reflecting changing disease epidemiology. Yet Sands et al. (2011) own study findings are incongruent with this suggestion since presenting illnesses remained similar over the ten-year period they studied. However, these can only be conjectures since information from analysing electronic data providing demographic and clinical coding information cannot give real insight as to why parents bring children with mild acute illness to the emergency department. The studies do not make any reference to the ‘appropriateness’ of attendance.

A slightly later study by Gill et al. (2012) using Hospital Episode Statistics (HES; a database detailing hospital admissions and emergency department attendance at NHS hospitals in England) explored rising emergency admissions for children with medical conditions usually managed in the primary care setting. It found a 28% increase between 1999 and 2010 (n = 81 vs 63 per 1000), with the greatest rise in children under the age of 5 years. The increase does not indicate that children are getting sicker; admission for the most common acute infections usually managed in the community (upper and lower respiratory tract infections, urine infections and gastroenteritis) rose by 30% (from 14.5 to 18.9 per 1000), with same day discharge increasing twofold (from 18 to 37 per 1000).

The most recent study looking at hospital care for children and young people analysed HES data from 2006-2016 and similarly found a rise in attendance in infants (n = 25, 415 to 33,684 per 100,000 = 23%) and children under the age of 4 (11%) (Keeble and Kossorava, 2017). Interestingly, the study found a huge difference in the most common conditions diagnosed on emergency admission to hospital during this period of time. The most frequent diagnosis in 2006/07 was abdominal pain with a total of 59,966 admissions, whereas the most frequent diagnosis is 2015/16 was a viral infection with a massive admission rate of 91,386. The significant increase in admissions with viral illness is suggestive of the changing parental attitudes to their child’s health and the anxiety created by mild acute illness. Parental anxiety has been shown to influence the decision for admission, exacerbated by risk-averse health care practice (Watson & Blair, 2018, O’Dowd 2015). As a result of rising attendance, overcrowding in the emergency department affects the capacity to observe patients, putting junior doctors under pressure to admit within the four-hour target. Indeed, the study found the majority of admissions to the inpatient facility were via the emergency department (62%).

Although the studies vary slightly in the extent they portray rising attendance, they agree it is increasing significantly. The change in trends and help seeking behaviour demonstrate the increasing reliance on the emergency care system to meet the mild acute health needs of children.

2.7 FACTORS INFLUENCING EMERGENCY DEPARTMENT ATTENDANCE

Studies have established there are multifaceted reasons why children are brought to the emergency department. These tended to focus on two major issues.

2.7.1 Parental Perception and Severity of Illness

Studies emphasise parental uncertainty and worries around failing to recognise a serious illness. Hendry et al. (2005) looked at the characteristics and decision-making processes behind attendance to the emergency department in a children’s hospital. Parents reported feeling confident in dealing with their sick child and knowing when to seek help, whilst paradoxically reporting high levels of worry over the seriousness of their child’s condition despite being assessed as non-urgent by the emergency department. A similar study by Williams et al. (2009) explored parental motivation when presenting for non-urgent care and found the majority of parents cited their perceived severity of illness as the main reason (60%, n = 213 of 355), however 57% (n = 202) rated their child’s condition as moderately serious and only 11% (n = 39) regarded their child’s illness to be very serious.

Indeed, evidence from one study suggests parents were able to recognise their child is unwell, but had difficulty grading severity (McGovern et al., 2017). The study explored parental knowledge and decision-making by survey questionnaire of 200 parents who attended a paediatric emergency department. Parental reasons for attending described symptoms of an illness such as fever or cough, but also included the need for ‘peace of mind’ and reassurance that there was no serious illness. Yet a small study by Winskill et al. (2011) found parental perception of illness more reliable with only a few children not requiring admission or investigation, however this does not consider the cautious professional and the tendency to over investigate when caring for children in the emergency department (Blair, 2018).

Whilst many minor illnesses have a high prevalence among young children, they create high levels of anxiety in parents due to uncertainty around the symptoms and an overestimation of the danger of their child’s illness. McLauchlan et al., (2020) explored care-seeking behaviours and found parental uncertainty and low tolerance of risk were key drivers for attending the emergency department. They interviewed parents of low triage category children following a visit to the department. Parents anticipated their child would be assessed quickly by the triage system, and if it were confirmed they were very unwell, rapid intervention and treatment would be given. McLauchlan et al. (2020) believed that this system encourages the use of the emergency department compared to alternative services, particularly for anxious or uncertain parents. Even if there are long wait times, parents reportedly felt safer waiting in the emergency department than worrying at home. It would seem when parents feel they have lost control of the situation; they want to hand the responsibility over the health care professional (Butun & Hemmingway, 2018; Hugenholtz et al*.* 2009).

These findings are not new. A historic study by Kai (1996) sought to identify and explore parents’ concerns when young children become unwell. Ninety-five parents were interviewed and were asked to discuss freely what was important to them when coping with an unwell child and why. The importance of fever, cough and the possibility of meningitis were consistent findings, provoking fear their child may die or suffer serious harm. Parents observed their child closely and felt an overwhelming sense of responsibility to ensure the safety of their child. They expressed their frustration at feeling ignorant; worried they may be missing a serious illness. The study found parents were aware the symptoms of meningitis were rapid and non-specific and whilst they did not wish to ‘bother’ the doctor unnecessarily, parents felt they had little choice other than to share the responsibility with another. The work by Kai (1996) was in the context of the increasing use of general practice services. Later research does not show parental concern around caring for an unwell child has altered or intensified over recent years and hence cannot be a causal factor for the increasing rise in emergency department attendance. It is more indicative that the changes in availability to primary care services are affecting the attendance to the emergency department.

2.7.2 Attending the Emergency Department Instead of Primary Care Services

Studies show that parents would choose to see their GP but often reported difficulties in obtaining urgent GP appointments. Butun and Hemmingway (2018) carried out a qualitative systematic review of reasons for parental attendance to the emergency department and found that some parents were unable to get a GP appointment or were unwilling to wait and experience a delay in treatment. Others related that it was more convenient to attend emergency department ‘out of hours’ as they would not need to take time off work.

No appointment is required at the emergency department, parents feel assured their child will get assessed and treated quickly, and resources are readily available to carry out further investigations and obtain rapid results. However, the majority of parents would still prefer to use the most appropriate service for their child (McLauchlan et al. 2020). There has been discussion around the confusing array of urgent care options leading parents to default to the emergency department. McLauchlan et al. (2020) found that parents were aware of the alternative provision, yet more than half of the parents interviewed felt that the emergency department was the most appropriate place for their child on that occasion. Parents criticised the alternative urgent care services for their tendency to refer a child to the emergency department with half of the parents who were interviewed receiving this advice. They were clear that in future they would present directly to the emergency department without a referral from another urgent care service (McLauchlan et al. 2020).

A comprehensive study by Rowe et al. (2015) was commissioned by the Department of Health in which 35 parents of young children brought to the emergency department with mild acute illness in the previous 6 months were asked about the factors that influenced their decision to attend. Similar to McLauchlan et al. (2020), Rowe et al. found that the majority of parents understood that the emergency department is for emergencies, yet all had taken their child with a non-urgent problem.

They explored parental perception of the different healthcare services and found that parents held varying views of GPs. Whilst parents liked a personal relationship with their GP, particularly after a long period of time under their care, they felt that GPs lacked specialist paediatric knowledge and would probably refer them to hospital anyway. Many parents reported seeing a different GP each time they attended, particularly for urgent appointments, and found inconsistencies in advice and management between the individual GPs that often led them to seek a second opinion. The time constraints imposed on appointment times led to parents feeling rushed and perceiving that their child had not been examined properly. Subsequent advice on the management of their child's illness was not detailed or clear, or it was considered to be out of date or old fashioned. This compared negatively to the emergency department where parents felt that emergency department staff gave consistent advice, their child was comprehensively examined and observed, and medical information was current and up to date.

Parents equally had mixed reviews for the telephone advice service NHS111. While the service was considered to be convenient and easily accessible, parents did not feel that it was useful in urgent situations. The telephone operators were not clinically trained, and they would likely be referred to the emergency department anyway, often transported by an ambulance called by NHS111. Walk-in centres (WICs) were also considered convenient and accessible, however parents felt that they were not always appropriate for children or in urgent situations. The WICs were often very busy with long waiting times, whereas parents felt reassured in emergency department that the triage system would rapidly provide an assessment of their child.

The study concluded that parents considered emergency department to be the best option out of a range of alternatives despite acknowledging that emergency department is for emergencies and expressing doubt about the appropriateness of their attendance. The emergency department 'brand' is simple to understand and remains a constant and dependable service in the sea of health care change. These findings were substantiated by a study by Holden et al. (2017) who carried out fieldwork in 2 UK hospitals and a review of academic literature exploring why parents bring children with minor illness to urgent care or emergency departments. The study observed the interaction between parents, doctors and nurses and later interviewed parents recruited through ‘mother and toddler’ groups to gain insight into how children proceed through the urgent care system. Parents similarly reported negative encounters with GPs, describing the quickest way of receiving treatment was to attend the emergency department, the ‘path of least resistance’. They report positive experiences of the emergency department; a child friendly environment alongside an impression of being seen by experts in the management of sick children over a less authoritative GP.

Holden et al. observed how this is reinforced when all children, including those attending with very minor illness or injury, received a full assessment thus reinforcing the perception of illness severity and justifying the attendance. Contrary to other studies, Holden et al. felt that most parents bringing their child with non-urgent illness did not appear overly anxious, indeed many were apologetic for coming to the emergency department. Yet when parents express their concern that they might be worrying over nothing, staff offered reassurance that parents have done the right thing and were not wasting their time (Rowe et al., 2015).

It is apparent the comprehensive service offered by emergency department is attractive and encourages parents to feel confident this is the best service to access should their child become unwell again. Indeed, one study found 71.5% of 200 families included in their research had prior experience of attending the emergency department with their child (McGovern et al. 2017). Standards ensure the environment is pleasant for children and there is access to paediatric specialists (Royal College of Paediatrics and Child Health, 2018a). Instilled in the paediatric nurse is the delivery of family and child centred care, an inclusive concept of parental partnership and care of family members as well as the child (Franck & Callery, 2004, O’Connor et al., 2019). There will be reluctance to offer overt criticism to parents for choosing emergency department for non-urgent care. Undeniably, the idea of discouraging, chastising or stigmatising parents would lend itself to critical ethical consideration (Holden et al., 2017).

2.8 PARENTAL FEELINGS AND BEHAVIOUR WHEN CARING FOR A SICK CHILD

A study by Neill et al. (2013) set out to look broadly at how parents behave in response to childhood illness. Parents of children aged 0-9 years were approached in non-health care setting, capturing a population of parents with young children most likely to be susceptible to childhood illness. Parents were invited to contact the researcher if their child experienced any illness and interviews then took place shortly afterwards. Over an extended six-year period, data was collected on four occasions, 15 families took part in the study, and 29 interviews were undertaken.

The study found that parents attempted to ‘do the right thing’ by conforming to informal social rules, initially imposed by family and friends. Parents preferred to share stories or seek advice from lay experts who they perceive as less threatening. However, the majority of health knowledge was found to come from contact with health professionals with parents learning more powerfully from negative encounters. Negative encounters were reportedly related to the perception of felt criticism (criticism communicated by attitude) or enacted criticism (direct or verbal criticism). Importantly, it was observed parents fearing criticism avoided asking questions during a consultation and left still feeling anxious about their child, unequipped to manage, and need to seek advice again.

This finding is interesting when considering the rise in attendance to the emergency department where Neill et al. believe relationships are transient and ‘one off’ encounters with staff that are considered less likely to generate criticism. Yet patients have not escaped censure by attending emergency department where the term ‘inappropriate attenders’ was often given to patients attending with apparent non-urgent problems deemed manageable in a primary care setting (Hendry et al. 2005; Patton et al. 2012; Watson & Blair, 2018). Conversely, Neill et al. report the findings of one parent who felt criticised for not seeking help sooner after visiting the GP with their very unwell child who was subsequently hospitalised. Neill et al. perceive this as the risk of criticism balanced with the threat to their child’s health.

Gender was found to influence perception of criticism, with fathers reportedly finding their concerns taken seriously and feeling less criticism whereas mothers were more likely to feel labelled as ‘fussing’. According to Neill et al. this illustrates differing informal social rules that serve to reinforce traditional gender roles, a subject with fascinating potential for future research. Neill et al. claimed that the ambiguity around the change in social expectations had resulted in parental sensitivity to how they are regarded by others, parental desire to be seen as ‘good parents’, and parental self-esteem dependant on the positive regard of others. These were portrayed as new concepts in response to changes in modern society such as engaging more mothers in the workforce and fathers in parenting, yet their supporting references are historic. For this reason, there is little acknowledgement of the role of the media, and any increasing anxiety created by the meningitis campaign.

By comparing research data only to social rules of behaviour, the findings of Neil et al. focused only on relationships between the health professional and the parent, power imbalance and its subsequent influence in help seeking behaviour. It is implied that parents would prefer to self-contain childhood illness at home rather than seek help which is not reflected in emergency department attendance data. In contrast, the findings of Rowe et al. (2015) established a difference in parental attitude with concern for their child outweighing any sense of loss either to themselves or NHS resources.

The psychological motives behind parents attending emergency department were explored in a study undertaken at one emergency department in a children's hospital (Costet Wong et al. 2015). A total of 497 parents completed an in-depth questionnaire based on the categories of motives whilst their child was waiting to be seen in the emergency department . Interestingly, younger parents were more likely to consider the emergency department as the best place to go, characteristic of the prevailing trends of increasing access to urgent care services. Seeking reassurance and consideration for their child's suffering were found to be high motivators for attendance. Similar to Neill et al. (2013) and the earlier study by Kai (1996) however, being considered by others a responsible parent was also rated highly, believing this demonstrated responsible and loving parenting.

There were limitations to the study by Costet Wong et al.; this was one hospital site and responses were limited to the choice of available answers listed in the questionnaire. Yet the authors were able to conclude the setting that seems to soothe the emotional motivators of anxiety and distress and assist parents in achieving their desire to be seen as a responsible parent, is the emergency department.

2.8.1 The Influence of Social Networks, Social Media and Mainstream Media

Research has found social media and online social networks can increase parental anxiety by sharing negative experiences and have created new sources of additional pressure on parents to be seen as responsible and reactive. Many parents reported feelings of confusion from advice posted on forums and searching the Internet often heightens anxiety by retrieving sites describing the possibility of serious illness (Rowe et al. 2015). Parents were encouraged to attend emergency department by family members, peers and by the online advice they have sought and will prefer to take the 'safe option' rather than risk being perceived a bad parent (Ogilvie et al. 2016, Holden et al. 2017). The media campaigns and portrayal of meningitis and more recently, sepsis were also seen to increase anxiety and help seeking behaviour (Holden et al. 2017).

2.8.2 Parental Expectations

Satisfaction with services occurs when parental expectations are met. An early small study by Woolfenden et al. (2000) established that parents want good communication from the health professional and the assurance their concerns have been considered. The parents anticipated a thorough physical examination of their child by a health care professional with clinical expertise and knowledge as they wanted to feel reassured their child had received the best possible service. Furthermore, they did not want to be made to feel like a 'panicky' parent if they had perceived their child's illness to be serious. The study by Maguire et al. (2011) found parents experience increasing anxiety when they feel they are not listened to or dealt with unsympathetically. They valued services that considered the practical aspects of caring for small children. Parents increasingly wanted a rapid assessment and described finding the advice to wait and watch difficult to follow, preferring the instant gratification of attending the emergency department when feeling anxious (Rowe et al. 2015).

Meeting the expectations of parents is an important consideration when exploring help seeking behaviour. If the quality of care is perceived as poor, families will continue to access multiple health services until reassured their child has received the appropriate treatment. Often information giving is sufficient to increase parental confidence and improve health literacy when caring for an unwell child (Warren &

Gite, 2017) but this takes additional time, which for many health care professionals is limited, and its value is commonly overlooked.

2.9 CONCLUSION

The literature confirmed that there is a rising trend to bring children with non-urgent illness to the emergency department and that the reasons behind the increase are multifactorial.

Parents are concerned that their child, even when exhibiting symptoms of a mild acute illness, may be experiencing the early signs of a more serious bacterial illness such as meningitis or sepsis. Media campaigns raising awareness of serious illness but without providing full education have served to cause alarm and ‘risk averse’ behaviour. Parents are frustrated at their lack of knowledge and loss of control and will actively seek reassurance, risking feelings of being criticised for the sake of their child; they would rather be ‘safe than sorry’.

Yet parental concern has not increased or changed significantly to account for the rises in emergency department attendance however the delivery of acute health care has changed. There has become a confusing array of urgent care providers with the government encouraging the public to choose the correct service specific to their need. In situations considered an emergency, emotions such as anxiety and fear cause parents to enter a ‘hot’ state of decision-making. The easiest decision is to access the constant, consistent and easy to understand emergency department service.

There is increasing interest in the motivational factors behind paediatric emergency department attendance, but this has not yet been fully captured as research undertaken so far has employed a prospective or retrospective approach exploring what action parents might take, or what action they have taken after a period of cooling down and reflection.

The challenge of rising emergency department attendance has to be addressed by modernising urgent care services to meet the change in the demand. The demands will be firmly identified by addressing the gap in the research by listening to parents and the ‘hot’ decisions they make as they seek help in caring for their sick child.

CHAPTER 3

Study Design

3.1 OVERVIEW OF THE STUDY

Despite the Department of Health’s best efforts to divert non-urgent patients away from emergency departments to primary care services, the number of children visiting an emergency department with non-urgent conditions continues to rise annually, with paediatric attendance representing over 25% of the total workload. While there is much research around the types of conditions with which children present at an emergency department, there are few studies exploring psychosocial drivers behind parental decisions to bring their child to the department.

A pragmatic qualitative approach was chosen, based on the proposition that pragmatism employs a flexible approach to research design that is focused upon the question and the consequences, rather than the methods. By moving between deduction (quantitative methods) and induction (qualitative methods), pragmatism can create both data and theories (Kaushik & Walsh, 2019). In this study, the approach combined the factual (the commonalities of attendance), and addressed the multiple realities that are the parents’ experience.

Using purposive sampling over an eighteen-month period, parents of children age 0-16 years presenting with non-urgent conditions as identified by the Manchester Triage Tool (Mackway-Jones et al*.,* 2013) were approached to take part in the study. Prior to discharge, focused interviews were conducted to explore the antecedent decision-making factors leading up to attendance. A follow-up interview via telephone was intended to take place 48 hours after leaving the department, enabling parents a period of time to rest and reflect on their experience and ascertain how this correlated with their expectations.

3.2 PATIENT AND PUBLIC INVOLVEMENT

To ensure that the recruitment process was feasible, and to establish the most appropriate timeframe within their emergency department visit to conduct the interview, patient and public involvement was sought first to strengthen the quality and ethics of the research (National Institute for Health Research, 2014). This was undertaken prior to the development of the GRIPP2 checklists (Staniszewska et al., 2017) however, a retrospective review indicated that the process conformed to the aims and methods of the GRIPP2 short form. The aim of the PPI was to establish the willingness of parents to participate in the study in a stressful situation. A total of ten parents who attended the department with their children over a two week period and who met the intended sample criteria were asked informally, as part of the PPI process, about their thoughts on the study purpose and design. The parents were considered to represent the varied age groups and ethnic backgrounds of parents likely to be approached to participate in the study. On six occasions, both the mother and father were present and were able to contribute to the process. Every parent who was approached was willing to share their personal experience and what would be important to them if they were asked to participate in a study in their current situation. Specific issues such as the best time to be approached and whether or not the researcher should wear a work uniform or own clothes were considered.

The conclusions from the PPI established that parents would be more inclined to participate in the interview once their child had been examined by a clinician. They wanted to feel reassured that their child’s condition was considered stable, and then their own anxiety would be reduced. Since this was also the researcher’s place of work, parents expressed a preference for the researcher to wear a uniform. This conveyed reassurance that clinical support would be readily available should the child’s condition change during the interview. The notion of the child remaining safe was clearly of great importance to them. They preferred that the interview should not be recorded, but hand-written notes taken instead. Similarly, parents agreed that they would be more likely to agree if the telephone interview were not recorded but would accept hand-written notes being made.

3.3 RESEARCH QUESTIONS AND OBJECTIVES

The research question was **‘What are the expectations and experiences of parents who bring their child to the accident and emergency department with non-urgent medical illness?’**

Objectives

1) To assemble a varied sample of parents of children presenting with a variety of non-urgent medical illnesses (triage score 3 or 4, or 2 and discharged home)

2) To identify predisposing factors behind the decision to attend the emergency department. These might include the concern for their child, previous help and advice sought, previous experience of services or having an unwell child.
3) To explore parental thoughts and feelings about caring for an unwell child and accessing support from health professionals and services.
4) To elicit the expectations held by parents of the health service that would be offered, their perceived response from the health care professional caring for their child, and the outcome of the visit.
5) To establish parental perceptions of the outcome of the encounter, and how expectations matched their experience.
6) To gain insight into what service parents would like to access when their child is unwell.
7) To identify potential strategies to impact positively on parental experience and service development.

3.4 SAMPLE

3.4.1 The Sampling Frame

The sampling frame comprised of parents of children aged 0-16 years presenting with an acute illness at the emergency department of one district general hospital with a demographic situation and attendance typically representative of a local population. This profile was typical of many towns and cities in the North of England. It was intended that non-English speaking parents would be invited to participate if an objective interpreter could be secured, however, all participants were able to understand and speak English.

The emergency department in this study received approximately 5000 children per annum attending with medical illness who would subsequently be discharged home. This meant that recruitment of sufficient participants of varied characteristics should be possible within a short period of time. The data collection process took place over an 18-month period until the desired maximum variability of the sample was achieved. The inclusion of key characteristics and attributes was more important than the number of participants for this study. For planning purposes, initially a loose aim of recruiting approximately 50 participants was considered in order to present convincing conclusions with all relevant variables represented. However, restrictions imposed by the COVID pandemic drastically reduced attendance by children in emergency departments throughout the UK curtailing recruitment to 35 parents. In total, 37 parents were approached. Agreement to participate was overwhelming positive with parents appearing to welcome the opportunity to share their experiences. Only two parents declined: along with her child, one mother felt unwell, and one father needed to leave to go to work.

3.4.2 Purposive Sampling

Purposive sampling was used, strategically selecting only participants relevant to the research question (DePoy & Gitlin, 2005). Purposive sampling is a method undertaken in qualitative research, and whilst this study included quantitative data, too, it was intended that this would provide context to the qualitative data rather than form a primary focus. A non-probability approach does not allow results to be generalised to the whole population (Bryman, 2013), but it was appropriate for this exploratory study, which was the first of its kind to consult parents directly in this manner and to compare expectations with actual experiences.

3.4.3 Maximum Variation Sampling

In an attempt to collect data from the widest range of perspectives possible, maximum variation sampling was adopted to anticipate the characteristics that might be important variables in the study. From the PPI, it emerged that both mothers and fathers might have different views, as might younger or older parents or others with caring responsibilities such as grandparents. Ethnic origin combined with cultural differences might be expected to be important factors in decision-making, as might the age of the child and the nature of the illness. The availability of specialist paediatric community services (such as a children’s community nursing team) might play a part in the degree of access to alternative helpful primary care options.

It was determined that these factors would be included during sampling and when collecting data. However, as additional issues came to light once data began to be amassed, then additional variables were expected to be identified. A greater number of variables to be considered would increase the size of the sample required to ensure adequate coverage of these variables.

3.4.4 Triage Scoring

All patients on arrival to the emergency department are assessed using the Manchester Triage System (MTS). The MTS is a triage algorithm consisting of 53 separate flowcharts based on the patients presenting complaint. Based on the signs and symptoms, it allows the triage nurse to prioritise the urgency at which the patient needs to be assessed by a clinician (Zakeri et al. 2022). The children assessed at triage to be of moderate to low priority using the MTS were the study population from which the sample was taken (a score of 3 or below indicates that the patient could wait at least one hour before being reviewed by a clinician). It is not uncommon that some patients triaged at level 2 may later be deemed to be less ill and may be discharged home without further treatment. These could also be included in the study.

3.4.5 Inclusion and Exclusion Criteria

Inclusion criteria

Children of 0-16 years, who were brought to the emergency department by an adult with parental responsibility, with a triage score of 3 or 4, and whose parents were willing to undertake both elements of data collection met the inclusion criteria.

Exclusion criteria

Children whose clinical or social issues identified by the triage nurse could be aggravated by inclusion were excluded. Any safeguarding concern, or inability of the parent (or other responsible adult) to hold a conversation in English or with an available interpreter also resulted in exclusion. Children who were accompanied by a foster carer or who had a child protection plan in place were excluded as the threshold for attending an emergency department has been observed to be lower as children’s social care agencies will, as a precaution, advise medical assessment of the child.

The researcher checked with the attending nurse that there were no circumstances that would indicate that an approach to participate would be inappropriate. Any safeguarding concerns are highlighted during triage, and as a senior nurse in the department, the researcher would have been made aware of this discreetly. Safeguarding concern was an absolute exclusion criterion for recruitment.

3.4.6 Avoiding Research Bias

Families were approached to participate and given written information following the allocation of a non-urgent triage category, and the interview was conducted before they left the department. As a single researcher, potential problems could occur if more than one family met the criteria for inclusion at any one time. The time constraints and capacity of the emergency department also impacted on collection of data with the potential for researcher bias in choosing the most expedient patient subjectively. Ongoing active awareness of this possibility was maintained, and the diversity of the sample was checked routinely in supervision meetings.

3.5 DATA COLLECTION

3.5.1 Semi-structured focussed interviews

Once consent to participate was obtained, data was collected using semi-structured focussed interviews. Semi-structured interviews have the advantage of exploring pre-determined topics while being flexible to include unpredicted issues salient to participants. Prompts from the researcher can allow responses to be elaborated and expanded (Tod, 2010). The focussed aspect of this means that the researcher has a mental list of issues that should be addressed, though not necessarily in a set order or through clearly planned questions. As long as the respondent talks about issues that are relevant to the research questions, the researcher will not intervene to redirect the conversation. However, if the responses become clearly disconnected from the main focus, the researcher gently and politely guides the respondent back to the central issues.

Clearly, this method is limited in its dependence on the interview skills of the researcher, and it is suggested that as the study progresses, experience gained and skills honed will potentially engender differing responses from the interviewees (Gilham, 2000). However, given that many of the skills of research interviewing are those required in nursing practice, and that the topic in question was within the realm of expertise of the researcher, the necessary skill set was already developed. Some practice interviews with colleagues and then with the PPI parents ensured that the interviews were conducted effectively. Differing from a pilot study, the practice interviews enabled the process, rather than the questions, to be refined (Gillham, 2000). These were conducted by seeking the opinion of parents who would normally meet the study criteria on the timeframe within which they would be most willing to participate in the interview and other issues as identified in 3.2 above.

3.5.2 Location and Timing of the Interviews

Location

Once the child had been triaged, parents were approached and invited to participate in the study. Information about the study was given along with the consent form and time was allowed for the parents to read through the information. Following the medical assessment, the interview took place while the child remained in the patient cubicle. It was ensured that the child was comfortable and activities were provided while the interview took place. Despite the busy nature of the environment, efforts were made to convey time to talk and the interview was conducted while seated and with the curtains closed to minimise distractions. Privacy throughout the interview was consistent with what patient received during their assessment.

Timing

Discerning the best time to conduct the interview can be sometimes problematic. Following the suggestions from parents who participated in the PPI, the interview was conducted after the clinical decision had been made. This had the advantage of parents being more willing to participate once their child had been assessed, and potential high levels of concern for their child alleviated. A perceptible disadvantage of this approach was the time required to conduct the interviews (De Poy & Gitlin, 2005), particularly in a busy emergency department. Further prospective disadvantages were parents being anxious to go home once their child had been assessed. Since the study was exploring preceding expectations about attendance, conducting the interview at this point relied on parents reporting somewhat retrospectively on their expectations while also reflecting on their new position in the light of their experience. The prospect of later interpretation of the initial expectations was a threat to validity. This was avoided when the opportunity to conduct the interview was taken during a period of short observation in the department prior to discharge. This might have been to allow for symptoms to improve following treatment, or if the family were waiting for further information or a prescription.

3.5.3 Closed Questions for Demographic Data

This study incorporated a small number of closed questions to define, for example, any previous exposure to the emergency department, the age of the child and features of their illness, the time of attendance, and if the parent had previously consulted any other health care provider. Additional data would normally be available from the patient record, but if missing, would be asked for at this point.

3.5.4 The Main Part of the Interview

Open questions explored themes such as making the decision to attend emergency department and the feelings generated by that decision; what parents anticipated and expected from their visit; what instilled parental confidence in a healthcare experience; and the type of service they would like to have available when their child was unwell. During the follow-up interview by telephone 48 hours post discharge, parents were asked to reflect and rationalise upon their visit to the emergency department. Factors such as experiences matching expectations, effect on parental confidence, and management of their child should they become unwell again in the future were then explored.

It was anticipated that parents may have some reservations about expressing their thoughts and feelings to a researcher who was part of the team being explored in the interview process. This however was not found to constrain parents. Instead, parents seemed to value the opportunity to share their experiences and opinion to a HCP working in the urgent care system.

For both elements, hand-written notes were taken throughout the interview process and these were checked for accuracy with the participants at the conclusion of the interview. Taking notes was not shown to obstruct the flow of conversation. By taking a few moments to write, it seemed to give parents some time to articulate their thoughts and recall previous experiences that they then shared. Often, parents would add more detail as the notes were reiterated at the close of the interview.
Later, the notes were typed in full, and field notes were added to explain, supplement and clarify what had been discussed.

Problems could arise in contacting parents or if they changed their mind and no longer wished to participate. However, response rates tend to be better if prior consent has been obtained, the participants are aware of the purpose of the research, and an appointment time agreed to make the call (Gilham, 2000). In this study a maximum follow up time of 4 days was planned, with two attempted calls on day one, and one call on subsequent days. After this, no further follow-up was attempted. Consent formed two parts to enable the first set of data to be included in any analysis in the event that the telephone interview did not take place. Only seven telephone interviews were conducted, with participants having very little to add to the data. Following the onset of the COViD-19 pandemic, it was not considered appropriate or necessary for the researcher to attend the hospital solely for the purpose of completing telephone interviews. This aspect of the planned study was abandoned as being both unwanted by participants and ineffective in generating further data.

3.6 DATA ANALYSIS

The chosen approach for data analysis was thematic analysis, commonly used in qualitative research for its ability to examine themes or patterns of meaning within data. It is appreciated by novice researchers for providing the opportunity to learn basic data handling and coding skills, and for its step-by-step process (Braun & Clarke, 2013; Smith & Firth, 2011). A main strength of thematic analysis is its flexibility and ability to answer many types of research questions. It can be used to develop a detailed and descriptive account of what was happening, identifying the assumptions and meanings in the data (Braun & Clarke, 2013). Further advantages of this method are the systematic and visible stages of the process. It identifies relevant data to illustrate themes and determines whether there is sufficient evidence for a proposed theme. There is transparency in the researcher’s interpretations of participant experiences (Gale et al., 2013; Lacey & Luff, 2001). It was acknowledged that this would be a lengthy and time-consuming process, especially during the coding process (Smith & Firth, 2011). The procedures for analysis are summarised by Gale et al. (2013) and Braun & Clarke (2013).

- Stage 1: The collection of data and transcription.
- Stage 2: Familiarisation with the interview.
- Stage 3: Labelling or ‘coding’ the data to enable it to be classified and compared systematically with other parts of the data set.

- Stage 4: Using the firsts sets of data to group the ‘codes’, searching for themes working towards an analytical framework.
- Stage 5: Reviewing the themes and applying the analytical framework to identify the relationships between them.
- Stage 6: Charting the transcript data into the thematic framework matrix.
- Stage 7: Interpreting the data - eventually characteristics, similarities and differences were successfully identified across the dataset as the mapping of connections between themes and relationships and/or causality began to emerge.

The volume of data collected from 35 interviews was extensive. A table was devised that organised data extraction under codes and then under emerging themes (see excerpt from thematic analysis framework, appendix G). While this was a very time consuming process, it made it possible to identify commonalities in the shared experiences of parents seeking help in caring for their unwell child. The data analysis began as the interviews progressed. This allowed the process of the interviews to become more focussed and refined when seeking to expand the code and themes that were already emerging. It was decided that data sufficiency was reached when no new themes were emerging from the interviews.

3.7 ETHICAL ISSUES

A risk analysis approach was adopted (Long & Johnson, 2007) rather than commonly used principles-based approaches. Risk-analysis involves identifying actual or potential risks to participants and then working to eradicate, minimise or prepare for the occurrence of the risk. Two main risks were present.

3.7.1 The Risk of Perceived Coercion

Although there was no requirement to take part, it was possible that some parents might have felt obliged to do so. Families might be concerned that they would be treated differently if they refused to participate in the study. Since they could be in a vulnerable position and in a heightened state of anxiety due to attending hospital with their sick child, consideration to the timing of the invitation to participate, following triage and confirmation that the child was in no danger, was crucial.

It was also important that clear and accurate information about the study was provided in a printed information sheet. This explained the study, stated what would be required of participants, assured the right to decline or to withdraw at any time without needing to provide an explanation, and clarified how further information could be obtained. Signed consent was requested in order to evidence the recruitment of willing, informed participants.

The interviews were conducted sensitively however, should the parent have become distressed at any time, the interview would have been halted immediately, appropriate support given and any data discarded.

3.7.2 The Risk of Breach of Confidentiality

In any study that involves NHS patients being recruited partly as a result of their clinical information the risk of breach of confidentiality must be considered, together with the potential outcome of realisation of that risk. In this study, no treatment or care was to be affected or amended in any way by the study. The clinical decision had already been made and was not the subject of the study. No clinical details were recorded for the study, no NHS data was removed from the NHS, and no personally identifiable data was included in the study data. The level of risk was therefore particularly low.

To preserve anonymity, a study number was recorded on documents rather than names or NHS identifiers. Consequently, no names or other personally identifying data could be included in reports, publications or presentations. Data was stored securely on a password-protected computer, and hard copy files were stored in locked filing cabinet with access restricted to myself as the researcher, and my educational supervisor (DePoy & Gitlin 2005; Johnson & Long 2010). A register of participants (with corresponding study number) was made but retained by the NHS trust R&D department for destruction as soon as possible under GDPR guidance.

Parent were advised prior to agreeing to participate that an exception to confidentiality would occur should the interview disclose any poor practice, safeguarding or child protection concerns. This information was contained in the patient information sheet attached to the consent form. The data would be excluded from the research and information shared with other agencies to protect the welfare of the child and family.

3.7.3 Research Ethics Committee Approval

Formal ethical approval was secured from the University of Salford (ref: HSR1819-031) and from the Health Research Authority (HRA) following scrutiny by the NHS Research Ethics Committee (ref: 19/NW/0278, IRAS Project ID 244800). In practice, no unexpected ethical issues arose, and there was no breach of the protocol that was approved by the University Research Ethics Committee or by the HR.

CHAPTER 4
FINDINGS

4.1 INTRODUCTION

A total of 35 interviews were conducted over an eighteen-month period. This was modified from the original study design which anticipated that 50 participants would be interviewed over a three-month period. Initially, recruitment was slow due to the department experiencing higher levels of activity which constrained the time and space for the interviews to take place. The subsequent onset of the COVID-19 pandemic then saw a significant reduction in the numbers of children attending the department with mild acute illness. This was a national and international phenomenon (Goldman et al., 2020, Lazzerini et al., 2020, Roland et al., 2020).

It is acknowledged that recruitment does not always go to plan when the research takes place in a challenging and changing environment such as the emergency department (O'Brien & Black, 2015). Instead, obstacles can be seen as opportunities to respond and develop the study design. As the attendance of suitable participants reduced, the time period for data collection was extended, in part to allow for the data to capture any influence on parental behaviour as a result of the pandemic. A practical decision was made also to reduce the number of interviews in view of the ensuing time constraints of the study and the numbers of suitable and available participants. Ultimately, the data elicited from 35 interviews were considered sufficient to generate enough evidence to answer the research question. This decision was based on the diversity of the sample, the unexpected quality of responses, and the novel insights revealed.

The first aspect of the study findings is presented from demographic data, for example, the age of the child and the types of illness. It is, therefore, quantifiable, reporting more obvious or semantic meanings. As analysis continues through the ensuing themes, the latent meanings behind what is explicitly stated by parents was considered. These findings will be discussed alongside relevant literature.

Seven distinctive themes were identified, and though themes did not overlap, many were closely related, and in some instances, the data was difficult to isolate into one theme. For example, the mother in interview 34 reported *"I've come because the GP* *surgery told us to come, but all this could have been avoided. I just needed to speak to someone, get some advice."* From one statement emerge a number of discernible concepts: the parent's concern for their child; their doubts that they could continue to care for their child without getting advice and their need to speak to someone; their help-seeking actions and attempts to access the most appropriate service; the parent's perceived requirements from the encounter which differed from the advice given; and the implications then of having to acting upon that advice believing that they had no choice but to respond to a voice of authority. For this reason, the same data extract may be referred to more than once to support the discussion of different themes.

Braun and Clarke (2012) say that good thematic analysis will have defined themes that are unique and specific and that can be summarised in a few sentences. The seven themes and subsequent sub-themes in this study that capture the experience of parents seeking help for their unwell child are defined in the table below.
A final section considering the impact of the COVID pandemic on how parents cared for their child during this time is included at the end of the chapter.

Table 5 : Themes and sub-themes

THEMES	Sub-Themes
Seeking advice before attending the emergency department Parents explained how they had sought advice from various sources to support their help-seeking, or if they had made their decision autonomously.	• *Whose opinion mattered.* • *Were you advised to come to the emergency department?* • *A search of the internet*
The feelings that drive the action Parents described their anxiety for their child, their sense of responsibility and wanting help to assess and manage the potential risk of a serious illness.	• *The responsibility; "It's better to be safe than sorry."* • *The risk; "Could this be Serious?"*
When parents experience conflict and criticism Parents want to do the right thing for their child without increasing the burden on the health service. They explained how they navigated their feelings of conflict and the risk of receiving criticism over their decision to attend the emergency department.	*No sub-themes*
A justified attendance In contrast, other parents felt confident in their decision and identified the reasons that caused them to feel justified in attending the emergency department.	*No sub-themes*
Expectations It was anticipated that exploring parental expectations would be insightful for future service planning. However, few parents could articulate specific expectations of their attendance at the department.	*No sub-themes*
Experiences Parents were able to recognise what made their encounter with the health service a good or bad experience, and they were able to identify what they wanted from a health service designed around the needs of the child and parent**.**	• *Communication; feeling fobbed off and dismissed* • *Mixed Messages; "It was so inconsistent."* • *Frustration; "I felt so angry and let down."* • *Complex Journey: The Parent's Story*
What parents want Parents identified the important aspects of healthcare that they wanted to be able to access when their child was unwell.	• *Instant Access; "I don't want to wait when my child is unwell."* • *A Dedicated Paediatric Environment* • *Time for the Consultation "It all felt very rushed…it was such a waste of time."*

4.2 DEMOGRAPHIC INFORMATION

At the beginning of the interview, parents were asked a number of demographic questions to provide insight into the context of their help-seeking (Table 6). Of the 35 participating parents who were interviewed, 31 had prior experience of bringing a child to the emergency department. Eight families attended ‘out of hours’ from their GP surgery times, which was considered to be 9am to 5pm. Six children attended between 8am and 9am.

One child had travelled to the emergency department via ambulance, called out on the parents’ behalf by NHS111. Five parents had refused an ambulance and brought their child in their own transport; either the parent did not feel an ambulance was necessary or there were long delays for the ambulance to arrive. One mother had walked with her child intending to attend the Walk-in Centre, but then the child was diverted to the emergency department. Two parents used public transport.

Table 6: Summary of Demographic Data

AGE OF CHILD (years)						
≤1	2-5	6-12	13-16			
16	12	6	1			
CHILD ACCOMPANIED BY[1]						
Mother alone	Father alone	Both parents	Father + Grandparents	Mother + Grandmother		
26	1	6	1	1		
PRESENTING COMPLAINT						
Fever	“Not usual self” [2]	Rash	Cough and breathing problems	Diarrhoea and vomiting	Abdominal Pain	
13	11	6	7	2	3	
ADVICE SOUGHT PRIOR TO ATTENDANCE (could be more than one source)						
Internet	NHS111	Family or friend	GP	Pharmacy	Social media	Not sought
13	17	14	18	2	1	3
ADVISED TO ATTEND BY…						
Another HCP[3]	Other[4]	Own decision[5]				
19	7	9				

[1] During the pandemic only one parent was allowed to accompany the child.

[2] Often cited in conjunction with another presenting compliant/symptom

[3] After telephone consultation, direct review, NHS111 or GP.

[4] Family, friend or social media forum.

[5] Six sought advice from a HCP or family/friend first.

4.2.1 The Age of the Child Attending the Emergency Department

The majority of participants were parents of infants and younger children, a representation reflecting findings from earlier studies showing that children aged under 5 years form the highest percentage of child patients attending the emergency department (Gill et al., 2013; Holden et al., 2017; Keeble and Kossorava, 2017). Similar to the findings of Woolfenden et al. (2000) and Halls et al. (2017), it was a common for parents to describe a greater sense of helplessness for a baby or younger child who was entirely dependent on their care and unable to express how they were feeling, and for whom the parents felt there was a significant risk of developing a serious illness.

> *"He's really unsettled. We've tried everything now. We can't do any more for him because of his age*." **Father of 7-week-old baby – Interview 4**
>
> *"He's only a baby. I was worried it could be something serious. The baby can't tell you how they are feeling."* **Mother of 9-month-old baby – Interview 16**

Parents began to feel less anxious when their child was able to articulate their symptoms and were less vulnerable to developing a serious illness. Parents of older children, however, described their increasing concern when the illness lasted more than a few days or the response to the illness was notably out of character for their child.

> *"I panicked when I didn't know what was happening as it was so unlike her to be so unwell."* **Mother of 11-year-old child – Interview 3**
>
> *"She is staying in bed all day, feeling unwell and is in constant pain. We don't currently have any answers or a diagnosis, and she's not getting better."* **Mother of 14-year-old child – Interview 12**

4.2.2 The Accompanying Adult

It was anticipated that the study might detect any differences in maternal and paternal driving factors which led parents to take their child to the emergency department. However, the onset of the COVID-19 pandemic part way through data collection forced restrictions on the number of people thought safe to be in the department, allowing only one parent to attend with their child during the hospital visit. This limited the collection of insightful data. From the 35 interviews completed, 16 were undertaken prior to COVID restrictions. Ten children were brought by their mother, six children were brought by both parents, and one child was brought by grandparents with the child’s father arriving shortly afterwards. Nineteen interviews were completed during the pandemic; 18 children were accompanied by their mother, one child by their father.

If mothers referred to their partner during the interview, they were asked about any paternal concern. Mothers generally described the child’s father as being equally worried, some even more so.

> *“He would have brought him last night, but it was me who said we’ll just wait to see what he’s like in the morning.”* **Mother - Interview 21**
>
> *“He would have been here with me, but we thought they would only allow one parent in, so he’s at home, messaging me!”* **Mother - Interview 23**

While concern for their child appeared to be the same for both parents, there was a marked contrast in their response when asked if they had any concerns about being made to feel like a worried parent. Fathers were far less concerned about feeling criticised for their help-seeking.

> *“I’m bit worried about feeling like I am over-reacting.”* **Mother – Interview 1**
>
> *“I have never been made to feel in the wrong for seeking medical help, even when it turns out to be something or nothing.”* **Father – Interview 1**
>
> *“I might be being a bit dramatic.”* **Mother – Interview 4**
>
> *“I’m not bothered, I just wanted him to be seen.”* **Father – Interview 4**

Reflecting findings from other studies; fathers reported that they were listened to and taken seriously, so subsequently they did not experience the same concerns about feeling judged or criticised. Since it is the mother who will most frequently seek medical advice or intervention for their child, they are more susceptible to be labelled as ‘fussing’ (Neill et al., 2013; Norman et al., 2016). Parental feelings of conflict and criticism will be explored further in section 4.6.

4.3 THE SIGNS AND SYMPTOMS CAUSING PARENTAL CONCERN

The presenting complaints included fever, rash, cough/cold symptoms, abdominal pain, and the child differing from their ‘normal self’, reflecting some of the most common types of presentation to the emergency department (Halls et al., 2017; Keeble & Kossorova, 2017). Some parents cited more than one symptom.

4.3.1 Fever

Fever caused the greatest concern. Thirteen children were brought to the department by parents describing their child's high temperature as the main worry.

> *"He started some antibiotics yesterday for a urine infection, but he's still having temperatures today."* **Mother – Interview 29**

Fear of fever has been recognised for decades. In 1980, Schmitt wrote of the undue worry of parents of children with fevers, recommending routine health education to address 'fever phobia' (Schmitt, 1980). Forty years later, little appears to have changed, and he persists in promoting the benefits of a fever in fighting infection (Schmitt & Offit, 2020). As recently as 2021, a study by MacMahon et al. (2021) refers to fever phobia, finding that fever alone generated fear in 78% of parents. While a clinician can rationalise the role of fever as a normal physiological response to any infection and unlikely to be harmful, children often look unwell while their temperature is high.

> "*I was really worried about his temperature. It was 40 this morning and wasn't coming back to normal even with paracetamol. He was really lethargic, not his usual self and he wasn't drinking much either. But it was more the temperature of 40 and him being so lethargic*." **Mother – Interview 27**

Parents worry that this may be an early sign of a serious bacterial illness such as meningitis or sepsis, or that prolonged fever can lead to seizures and brain damage (Gunduz et al., 2016; Neill et al., 2014; Watson & Blair, 2018).

> "*His dad was worried too. He said they can have fits when the temperature is so high. And another one of his kids had meningitis and was really poorly.*"
> **Mother – Interview 27**

Paradoxically, official sources of patient information will reassure that a fever is very common in young children and a normal response to mild illnesses, however, the same sources rightly do not want to miss the child with a more serious illness so the advice is given to parents to seek further help should their child not want to eat, is not their usual self, or if the parent is worried (NHS, 2020). This description encompasses the majority of small children when unwell, so parents will find it difficult to differentiate what they can self-manage and how to alleviate their worry without seeking assistance.

> *"She's got this temperature. I was just getting worried. She's not her usual self."* **Mother – Interview 25**

4.3.2 Rash

Six parents were concerned about their child having developed a rash, being aware that this, too, could be a sign of meningococcal meningitis or sepsis. In four instances, this was the child's only symptom and the child was otherwise well. Two children were recovering from a mild viral illness but had then developed a blanching rash, a common and usually self-limiting phenomenon in viral infections (Knöpfel et al. 2019). Two parents discussed their use of the 'glass test', widely recommended by health organisations to establish if a rash disappears or remains visible when pressure from the glass is applied (NHS, 2019; NICE, 2020). Parents were aware that a rash that does not fade can indicate serious illness, and despite the child being well, described the anxiety that this generated.

> "*It was the rash and it not fading with the glass test. We were really worried."* **Father – Interview 5** (On examination in the hospital, the rash was found to fade under pressure.)

4.3.3 "Not Their Usual Self"

Alongside additional symptoms, 11 parents described their child as "not their usual self". Only one parent said this was their primary concern. Health organisations use the description "not their usual self' to describe general malaise or vague behavioural symptoms and encourage parents to seek medical help immediately (NHS, 2019). The lack of a clear definition was reflected in the difficulty some parents experienced in articulating their concern, but it emphasised to parents that there could be something significantly wrong if their child was quieter than usual, or not eating as much as they normally would. Generally, these children were assessed by the HCP in the emergency department to appear well. One child was observed to be running happily around the department whilst the mother maintained that this was still "quieter than his usual self".

Reflecting findings from previous studies, there is an obvious disparity between parental perception of what is considered abnormal for their child, and a change in behaviour that indicates to the HCP that the child has a serious illness (Hendry, 2005; McGovern et al., 2017; Williams et al. 2009). Yet vague guidance exacerbates parental anxiety when their child is behaving even slightly differently, and parents act upon advice and seek immediate help.

> *"They're not their usual self. I don't think it's anything serious. I just want peace of mind. It's better to be safe than sorry."* **Mother – Interview 10**

4.3.4 Cough and Breathing Problems

Seven children were brought to the department by parents concerned about changes in the child's breathing. Since respiratory illness is one of the most common reasons children are brought to the emergency department (Keeble and Kossorava, 2017), this is notably a comparatively small percentage of the study participants. It is feasible that the low representation of respiratory illness was a result of the onset of the COVID-19 pandemic and the subsequent imposition of restrictions on social gatherings, movement, the closures of schools and keeping children at home. The risk of children acquiring and spreading any infection was concurrently reduced and common childhood respiratory illnesses decreased (Kaur et al., 2021). The symptoms of the COVID-19 virus were typically respiratory, yet it soon became apparent that children were less likely to become infected, and those that did had mild or no symptoms (Zimmermann & Curtis, 2020). While the good news of the minimal impact on children was relayed to the public, daily media reports on the increase in cases and deaths from the virus continued to evoke fear and cause confusion (Young, 2021).

Three parents brought their child suffering with mild respiratory symptoms, expressing alarm that their child may have contracted COVID-19. One mother acknowledged that she would not usually seek medical help for a cough, and that she would usually manage this type of illness at home. Now she felt uncertain, describing the fear generated in herself and the child's father.

> "*It was his difficulty breathing; that he was tugging in; and his cough. I thought he might have COVID, well his dad did more than me. He was panicking. There's so much uncertainty about doing the right thing at the moment. I*

> *wouldn't have brought him to A&E with a cough before.*" **Mother – Interview 19**

Parents voiced their misgivings that their child may have COVID-19 yet conceded that there was no direct contact with any confirmed case of the infection or even anyone with symptoms, rather that family members were key workers with a higher risk of being exposed to the virus.

> *"I'm wondering if he may have COVID. We're both key workers, working with the general public. We're alright, but I'm worried we may have brought something home with us and passed it on to him. If COVID wasn't happening, I probably would have just kept him at home"* **Mother – Interview 23**

> *"All things have been going through my mind. His auntie is a keyworker, she might have passed COVID on to her."* **Mother – Interview 24**

For these families, parental concern was not triggered by the severity of their child's symptoms but rather the perceived threat of the COVID-19 virus.

Other parents were commonly worried that changes in breathing might indicate a chest infection or asthma that required management in hospital. Every child that presented with a respiratory illness had attended the emergency department previously. Although it was not always ascertained if this had been for the same type of illness, several parents reported that their child had experienced similar respiratory symptoms and had received treatment in the emergency department.

One mother admitted that she had brought her child at the first onset of symptoms, wanting to pre-empt any deterioration and alleviate her worry.

> "*I didn't want to leave him all night and be worried*." **Mother – Interview 15**

At the time of the medical assessment the child remained well and did not meet the threshold for any intervention. The family were discharged with written advice on looking after their child at home which included when they should seek a medical review.

Despite having a 'face to face' consultation booked with the GP later that afternoon, one mother felt that she could not wait at home with her child any longer. The child had also received treatment in the emergency department on a previous occasion, and the mother was anxious that he would need treatment in hospital again.

> *"We've got an appointment with the GP later, but he's not quite lasting 4 hours between needing his inhaler, so we've come here."* **Mother – Interview 32**

The clinical assessment established that no new treatments were required at that time, and the child was discharged back to the care of the GP.

Similar to the findings of McGovern et al. (2017), parents were shown to worry more after a previous experience of attending the emergency department with an unwell child. This led to early help-seeking in an effort to prevent any deterioration in their child's illness, and attendance was often prompted by parental anxiety rather than any significant clinical deterioration

4.3.5 Abdominal Pain

Three children, all aged over 12 years, attended with abdominal pain. Two were re-attending the department as a clear cause for the pain had not been established and their symptoms had not resolved. Both children had been investigated previously by having blood and urine tests. These had excluded a surgical or infectious cause, and the children had been discharged home without being given any further explanation for the pain.

> *"She was in so much pain. I've had to bring her back two more times before we've got a diagnosis of constipation. Now I know what it is, I feel more relaxed and we can manage things at home."* **Mother – Interview 3**
>
> *"I've little confidence in the consultations so far as they haven't received any answers or explanations."* **Mother – Interview 12**

Often parents will return appropriately with their children should their illness worsen, however both parents reported that the reason for their reattendance was that they did not know the cause of the abdominal pain and that their children were no better.

Re-attendance at the emergency department is a well-recognised and scrutinised problem. Rising et al. (2015) found that the most common reason for returning was fear or uncertainty about the illness. Indeed, both mothers remained uncertain and fearful from the lack of information about the cause of their child’s pain. There are occasions when the HCP will have to explain that they are unable to establish an absolute cause of the sickness or pain, but that their assessment has excluded a serious illness. This should be followed up with advice on how to recognise the warning signs and symptoms that require a further medical review. Unless parents receive effective communication from the health professional, they will continue to seek medical help until they feel that their child has been examined thoroughly and their concerns addressed (Woolfenden et al., 2000).

4.3.6 Diarrhoea and Vomiting

Two children attended with mild gastrointestinal symptoms. One mother had not sought any advice before bringing her new baby, feeling confident that she recognised the problem from her experience of having an older child. A midwife had visited the family the previous day, but the mother had not mentioned her concerns about the baby vomiting, or contacted the midwifery team again, preferring to bring the baby to the emergency department.

> *“I didn’t ask anyone this time. I recognised what was going on as my older daughter had the same thing when she was a baby. She was sent to the hospital, so I knew what would happen.”* **Mother – Interview 22**

The second mother had intended to bring her child to the walk-in centre, which is co-located with the emergency department. She wanted advice for her baby who had developed diarrhoea after stopping medication for constipation a few days earlier. The GP at the walk-in centre refused to see the baby, believing that it would be more appropriate to attend the emergency department. On reflection, while the mother valued the care that her child received in the department, she felt that her decision to attend the walk-in centre was correct.

> “*A&E was able to observe her for longer and re-assess her which gives me reassurance*, *but I still think the diagnosis of gastroenteritis would have been the same either way and the outcome would be the same*.” **Mother – Interview 7**

This is an interesting contrast in behaviour between a parent who had access to an appropriate service (the midwifery team) but chose to attend the emergency department, and a parent who chose the appropriate service (the walk-in centre) but was diverted by a HCP to the emergency department. A past experience of being sent to the hospital influenced the first mother to bring her new baby directly to the emergency department. She did not need to be told what to do this time. Her first child ‘had’ to come to the hospital, so she assumed this was the only place where her new baby could be assessed.

The second mother was able to recognise that her original decision to attend the walk-in centre was correct, but the challenge that her decision received could undermine parental confidence and affect future help seeking behaviour. The experience of both parents is not unique and is summarised by McLaughlin et al., (2020) who recognise that parents want to access the most appropriate service for their child when unwell. However, referrals to the emergency department from alternative services will influence a parent’s future decision to attend the department directly.

4.4 SEEKING ADVICE BEFORE ATTENDING THE EMERGENCY DEPARTMENT

Enquiring if parents had sought support in their decision-making prior to attending the emergency department was essential to investigating the influencing factors on care-seeking behaviour. Parents want to take the right course of action when their child is unwell and will often prefer to seek help and advice when their judgement is at risk of being affected by feelings of anxiety (Neill et al., 2014; Rowe et al., 2015). Parents were asked about the source of any advice sought; these may have included friends, family, the Internet, a pharmacist, their GP or NHS111. It was then determined if their decision to attend was advised or confirmed by another individual, if the parent was autonomous in their decision, or if they were acting entirely on the instruction of another health professional.

4.4.1 Whose opinion mattered?

Fourteen parents initially sought advice from a family member or friend. For a parent, seeking informal advice first may be considered to offer the lowest risk of receiving any criticism for their help-seeking actions (Neill et al., 2014). However, in this study it was found that family and friends consistently encouraged parents to seek an opinion from a more professional source, perhaps themselves preferring to avoid the responsibility and the risk of criticism for their advice.

> *“He’s got this rash. I spoke to my mum and she thought I’d best come and get him checked out.”* **Mother – Interview 5**
>
> *“My grandma said that she’s probably teething, but when she got the rash, she said it might be meningitis! She [grandmother] had meningitis when she was little, and told me I’d better bring her. She’s [the child] alright though. I think my grandma just thought it better to be safe.”* **Mother – Interview 24**

Twenty-five parents had contact with a health care professional prior to attending the department. Two parents had visited a pharmacy, 17 parents had telephoned NHS111 for advice, and 18 parents had a telephone or face-to-face consultation with their GP. Eleven parents had contacted both their GP and NHS111, some citing a deterioration in their child, others following the advice given by NHS111 to make an urgent appointment for their child to see their GP. One parent was unable to get through to the GP surgery so went directly to the emergency department.

Twenty-four parents sought information and advice from more than one source. This did not necessarily signify that parents were seeking confirmation of action or a second opinion, but often followed a pattern of speaking to a family member, who advised seeking a medical review.

> *“I wasn’t overly worried, but my mum thought I should ring NHS111, and they told me to see the GP. There were no appointments, so they advised me to come to A&E.”* **Mother – Interview 28**

Only two participants did not seek any prior advice either from informal or formal sources on how to manage their child’s illness before making the decision to attend. . Both parents cited their own previous experiences, from which they felt they could predict the outcome of their child’s illness.

> *“With his cough and recession, we knew we’d be coming to A&E anyway.”* **Mother** - **Interview 15**
>
> *“I didn’t ask anyone this time. I recognised what was going on.”* **Mother** - **Interview 22**

One mother did not actively seek advice but was told by her child’s school to seek a medical review.

> *"I wasn't overly concerned and probably would have waited, but he fell asleep in class and he hasn't been eating well for the last couple of days. School gave him some toast and a drink which made me feel like they thought he wasn't being cared for properly at home because he was tired and hungry. They said I need to get him seen. I've come here because you get a quick and full assessment in A&E."* **Mother - Interview 8**

The mother described the pressure she experienced from the school, referring to her concern that the school might have thought that she was not caring for her child and the inference that she was a bad mother. Her parental confidence and judgement were threatened, compelling her to seek an urgent assessment, which would be achieved most rapidly at the emergency department. This appeased her sense of taking the right course of action following the perceived criticism, and she could demonstrate to school that she was, indeed, a responsible parent. Neill, et al. (2013) write of the power of criticism, its influence on parental behaviour, and the desire to be seen as a good parent. Parental feelings of conflict and criticism are explored further in section 4.6

4.4.2 Were You Advised to Come to the Emergency Department?

Nineteen parents were advised to go to the emergency department either by the GP or NHS111. Seven parents had been advised by NHS111 to see their GP, but a lack of available appointments meant that they were diverted to the emergency department by the GP surgery. A study by Conlon et al. (2021) found that GPs' reasons to refer children to the emergency department include preferring to err on the side of caution (risk aversion), and parental anxiety with accompanied parental pressure to make the referral. Yet several parents questioned whether their attendance was necessary. Even after seeking advice, they felt that they had no choice other than to follow the instructions given.

> *"We didn't really feel A&E was the right place to come but we followed the advice."* **Mother – Interview 27**

> *"I've come because the GP surgery told us to come, but all this could have been avoided. I just needed to speak to someone, to get some advice."* **Mother – Interview 34**

Berry et al. (2017) suggest that patients are reluctant to challenge the advice of the HCP, viewing clinicians as experts, and responding to a power imbalance between the socially embedded roles of the patient and the clinician. The higher the stakes of a health decision, the greater the patient's position of fear. For parents, the stakes are the requirement to be seen as a good parent, a vulnerability to criticism, and a fear of repercussions if they do not follow advice. Confidence and knowledge become crippled by worry and anxiety, and parents will prefer to protect their reputation as a good parent by appearing compliant and conforming to instructions (Neill & Coyne, 2018). It was evident, however, that some parents could demonstrate a greater sense of the appropriateness of their attendance to the emergency department than the referring HCP.

Alternatively, being advised to attend the emergency department caused some parents with initially low levels of concern to become seriously worried, creating a sense of urgency as they are caused to believe that the illness must be more serious than they realised. Parents then doubted their own ability to care for their child. Their confidence was challenged as they feared that they had failed to recognise the severity of their child's illness.

> *"I would have preferred to see the GP but when I rang them, they told me to come to A&E because he had a temperature. I panicked then; I've rushed up here."* **Mother – Interview 21**
>
> *"I wasn't overly worried. But when the GP told me to bring her to A&E, I panicked a bit. I questioned myself. I thought, have I missed something?"* **Mother – Interview 28**

The implications of being advised to attend by a HCP is discussed further in section 4.7.

4.4.3 A search of the internet

When asked if they had searched for their child's symptoms on the Internet, only 13 of 35 participants confirmed that they had done so, despite this being considered by some to be the most obvious source of instant information when a child is unwell (Neill, et al., 2014). It was observed that some parents seemed uncomfortable and were reluctant to share their Internet usage. Bryan et al. (2020) similarly found that 96% of parents disclosed that they had searched online for child health information prior to seeing a health professional, but only half of parents discussed their Internet findings with a doctor or nurse.

Perhaps the reluctance to disclose Internet-searching of symptoms is a result of commonly reported problems with unregulated and low-quality health information. Rather than offer reassurance, anxiety is intensified by conflicting information about the possible severity of their child's illness (Rowe et al. 2015; Walsh et al., 2015). Internet users searching for medical information are increasingly encouraged to be more suspicious of what they find (Battineni et al., 2020), yet parents, even when aware of the positive and negative aspects on online health information, have difficulty mediating the negative effects of what they see (Rathbone & Prescott, 2019). There are an increasing number of reliable internet sites that offer credible advice for parents of unwell children but are not well advertised

It may well be that that several parents were reluctant to disclose that their decision to attend the department was driven by fear exacerbated by an Internet search. Several parents recognised the shortcomings of searching the Internet and identified sources that they felt were trustworthy.

> *"I sometimes use the Internet, but I don't always trust the information. It can be a bit over the top."* **Mother - Interview 10**

> *"I didn't look at the internet this time. I've previously used NHS websites but find these generally advise getting an appointment or going to A&E."* **Mother – Interview 25**

The mother of an 8-month old baby who was 'not her usual self', was openly sceptical of the arbitrary Internet results.

> "*As the symptoms were a bit vague, it said it could be anything from growth spurt to autism!*" **Mother – Interview 1**

One mother was honest about her Internet usage and recognised that her continued search produced diagnoses that she knew were unlikely but still increased her anxiety.

> *"Her pain was much worse overnight. I was looking at the Internet. I kept clicking on links which were not helpful."* **Mother – Interview 14**

Social media forums for parents of young children can be considered a preferable choice over getting advice from a HCP. Parents often feel more comfortable asking one another questions rather than asking the HCP what might appear to be a stupid question, and they avoid the risk of being made to feel that they are an overanxious parent (Rathbone & Prescott, 2019). One mother described how valuable she found her online group.

> *"I follow the advice from my friends in the Facebook group. I trust their advice."*
> **Mother – Interview 10**

The mother had shown the forum a video of her baby's increased effort of breathing and had been advised by fellow members to attend the hospital. This appears to be typical advice from other parents via online social groups; obtaining a rapid health assessment is seen as a responsible thing to do. The potential seriousness of an illness is emphasised, and parents will encourage one another to seek professional help based on their own shared experience and that of people that they know (Doyle, 2013). On a previous occasion, the forum members had urged the mother to get a second opinion when her child was seemingly misdiagnosed. The child was subsequently admitted to the hospital for further treatment. This strengthened the mother's view of the value of their advice, and their support justified her decision to attend the emergency department. She did not appear to have any concern regarding which appropriate health service to access. She knew from past experience that she would be reviewed quickly in the emergency department, and both she and her peers would be satisfied with this course of action. The mother had given her forum peers a voice of authority, and, while it could be argued that she had to balance the risk of being criticised should she choose not to act upon their recommendations, she seemed willing to follow their advice unquestioningly.

4.5 THE FEELINGS THAT DRIVE THE ACTION

For most, parenting naturally brings an emotional responsibility to love and protect their child and to maximise the chances of survival (Abraham et al., 2014). The confidence of a new parent is likely to increase with time as they identify and react to infant distress, recognising and responding to needs such as feeding, comforting, affection and general tasks associated with caring for their child. The parent's actions are positively reinforced, and confidence increases as the child grows and develops healthily. Should the welfare of their child be threatened by illness, a less familiar experience for many parents, their confidence is challenged, and parents question their ability to continue to carry out their protective parenting role (Vance & Brandon, 2017). Throughout the interviews, I explored how parents felt and reacted when their child was unwell.

Parents often referred to their overwhelming sense of responsibility for their child and the anxiety associated with managing the risk of their child having a serious, even life-threatening, illness. For many parents, it was fear for the safety of their child that forced them to seek urgent medical help. Several parents were concerned at how quickly their child had become unwell. Others were concerned that their child had been unwell for days and that they should have been getting better by that point. They reached the conclusion that perhaps their child had a serious or sinister illness.

It was found that even the more experienced parents could not override their feelings of anxiety to reassure themselves based solely on their own assessment of their child's illness. Parents often felt that they were no longer in control and that it had become beyond their ability to care for their child without seeking assistance. An acute sense of vulnerability, fear and helplessness disempowered parents. These were often the drivers that forced parents to seek help and reassurance to re-empower them to continue the care for their child, thereby restoring parental confidence.

4.5.1 The Responsibility; "It's better to be safe than sorry."

Parents commonly referred to their sense of responsibility for a child whose welfare is reliant on their care. Responsibility brings a sense of accountability and having control. The anxiety and worry brought on by their child's sickness seemed to emphasise the parent's awareness of their accountability, but also threatened their sense of control. The safety of their child was dependent on their action or inaction, and since their child was displaying symptoms of a mild illness only, there was a sense of uncertainty over what action to take. There could be consequences for the child should their condition worsen, and for the integrity of the parent if they did not respond correctly, possibly preventing their child from becoming more unwell.

> *"I feel far more responsible because it's the health of my child. If it was me, I'd be less worried and cope better, but I can't do that with my baby"*. **Mother – Interview 1**

> *"It worries me. I'm the one responsible for making a decision about what to do, because the baby can't tell you how they are feeling."* **Mother – Interview 16**

Wanting to exclude a serious illness, and being unwilling to rely on their own judgement, the most responsible thing for the parent to do was to seek help (Hugenholtz et al*.,* 2009). In taking action, they were temporarily able to transfer responsibility to a HCP, trusting in another's knowledge and training to make the right decisions on their behalf. Parents often recognised that they simply needed to have their fears alleviated, admitting they that would not have been able to rest until they had received reassurance.

> "*I'm mindful it's likely just a cold but wanted peace of mind. It's better to be safe than sorry.*" **Mother – Interview 10**
>
> *"I hoped I would be seen quickly, told I'm over-reacting, and sent home."* **Mother – Interview 23**

A recent study by Biagioli et al. (2021) sought to address the pressures placed on emergency departments by mildly unwell paediatric patients, and continued to frame the parent as the problem, suggesting that the solution is to educate parents to distinguish between urgent and non-urgent conditions. Yet powerful emotions experienced by parents in this study concerned for the welfare of their child were seen to overrule any preceding knowledge or experience. One father was a veteran paediatric nurse yet recognised that worry altered his judgement, and he sought reassurance from another HCP to evaluate the risk more objectively.

> *"I'm not overly worried, but I need someone else to tell me not to be worried."* **Father** - **Interview 13**

4.5.2 The Risk; "Could this be Serious?"

Associated closely with the nature of responsibility is the concept of risk (Kermisch, 2012). Parents were often able to recognise the signs and symptoms that indicated that their child was mildly unwell. However, there were certain features of a minor illness that suggested the risk that it might be more serious. These might have been emphasised by health awareness campaigns, personal experience, or other family members and friends (Neill et al., 2014). The parent could not achieve peace of mind until their child had been assessed medically and the risk of severe illness excluded. One mother explained how worried she felt after seeing posters at her child's nursery and GP practice raising awareness of the signs of sepsis and meningitis. When her child developed a fever and mottled skin on her hands and feet, she recalled the advice given and sought urgent medical review.

> "*It was much better to be aware, but when you recognise the red flags, you fear the worse. I'm relieved, she's so much better after the Calpol."* **Mother – Interview 16**

A mother was asked about her concern that her child, who otherwise appeared well, might have a serious illness after the child developed a rash. The mother explained that she initially thought her child *"was alright"* but a family member had talked about meningitis, and consequently she doubted her own judgement and could not overcome the worry that her child's illness could be something more serious.

> *"I thought she was alright, just a viral thing. But then my grandma said that and then all things go through your mind, and you can't relax then. I've ended up coming up. It's not worth the risk.*" **Mother – Interview 24.**

For many parents, 'taking risks' with their child's health was unthinkable, and trusting their own judgement was seen as taking a risk. Similar to the previous case, another mother admitted that, even though she thought her child had symptoms of a simple viral infection, she could not trust or feel reassured by her own assessment and needed confirmation that the illness was of low risk to her child.

> *"I thought it hand foot and mouth but just wanted to check. I always think everything's serious. I don't want to take any risks with his health."* **Mother – Interview 33**

For some families, a rapid change in the child's symptoms caused significant concern, instilling a perception of urgency to manage the risk that this might represent a serious illness.

> *"We weren't messing about. We needed to go the quickest place when he looked so poorly with his temperature. We were very worried."* **Grandmother - Interview 9**

The child was in the care of the grandparents when parents were working; they felt particularly anxious with the responsibility of caring for him when he was unwell, and the additional burden of accountability to his parents to do the right thing. The thoughts and implication of them doing nothing about the perceived threat of a serious illness to their grandchild were unbearable. They had already taken him that morning to see the GP who "*couldn't find anything wrong*". They implied that they had little confidence in the findings of the GP as this time, *"we weren't messing about".* However, the child soon recovered to his usual demeanour after the administration of medication which returned his temperature to normal. Later, the family was joined by the child's father who defended the decision to attend to the emergency department, recognising that it was a response to the risk that the fever might indicate that his child had a serious illness.

> *"People will always rush with their child if they feel there is a risk".* **Father – Interview 9**

For one mother, it was the sudden unfamiliarity of her daughter's illness that made her think that the illness posed a serious risk. She described herself as an experienced mother and confident in caring for her four children when they were unwell, until the illness progressed beyond what she had previously encountered. She was caring ably for her teenage daughter at home by administering pain relief and warm baths but described feeling "*very panicky*" when her daughter suddenly became more unwell. The mother expressed her uncertainty about what was happening to cause the rapid change from being relatively well to very poorly. She no longer felt able to manage the new symptoms independently.

> *"I initially assumed it would just be a mild illness, probably a urine infection or something. It was the rapid way she changed and looked so ill. She went from having mild tummy ache to not being able to stand up. Her pain was so bad, and then being sick."* **Mother – Interview 3**

Her alarm at seeing her daughter so unwell led to the mother's swift decision to seek urgent support in caring for her child. The mother was relieved when the symptoms soon resolved. She went on to describe the emergency department.

> *"It was the best place to come when she was so poorly. I wasn't prepared to take the risk and just keep her at home. But now the pain has stopped and she's OK, she could have stayed in bed!"* **Mother – Interview 3**

As many children do, her daughter recovered quickly, and the HCP will see the child only when they are better, and they may question why they have attended the emergency department. Parents will often apologise and feel embarrassed following their arrival in the department (Rowe et al., 2015). Yet, hearing the mother describe her overwhelming concern and panic at the point when her child looked so unwell exemplifies why parents will develop a sense of urgency to seek medical assistance.

Indeed, some parents respond to the perceived risk to their child with what appears to the HCP unwarranted levels of anxiety. A study by Peeler et al. (2019) found that parents often feared the worst possible outcome for their child, whether this was a likely outcome or not. Their worry will continue to drive health-seeking behaviour until risk and fear are mitigated by the subsequent exclusion of a serious infection by a proficient and understanding HCP (Hugenholtz et al*.,* 2009). This was the case for one mother who described her overwhelming distress.

> *"I just felt so anxious and frightened"*. **Mother – Interview 30**

Her concern was reflected in the multiple contacts she had made with health services in her search for reassurance. Her young child had a short history of being unwell for one day with a mild rash and a fever. The mother had contacted both NHS111 and her GP, and she had attended the emergency department on two occasions within a 24-hour period. She continued to seek help until she was confident that the actions and the reassurance from the HCP were finally sufficient to alleviate her significant worry that her child did not have a serious illness. The multiple contacts required before she achieved satisfaction bring into question the quality of her experiences. The behaviours required of the HCP to instil confidence and convey expertise to the parent are explored in section 4.10 "What do parents want".

4.6 WHEN PARENTS EXPERIENCE CONFLICT AND CRITICISM; "I feel that we are judged."

Parental uncertainty and low tolerance of risk have been confirmed as key drivers for attending the emergency department. It is predicted that the process of providing a rapid triage assessment in the emergency department incites attendance as parents look to secure an urgent medical review to appease their worry (Halls et al., 2017; McLauchlan et al., 2020; Woolfenden et al., 2000). Yet the findings from this study show that the choice to attend the emergency department was more complex than simply low tolerance of risk and ease of access to a medical review.

Parents often negotiated feelings of personal conflict over their decision, wanting to access the resources provided by the NHS only when necessary, yet do the right thing as a responsible parent caring for their child. This finding is supported by existing evidence (Neill, 2015; Rowe et al., 2015). The dilemma over making the right judgement led several parents to feel apprehensive at the thought of being considered to be over-reacting by the HCP. Anxiety was heightened if a parent had experienced direct criticism on a previous attendance to the emergency department.

A mother and father recalled a previous occasion when they had urgently rushed their baby to the emergency department on the advice of NHS111. When they later needed a nappy and supplies for their baby, the parents felt criticised by a nurse who told them that they *“should be more prepared”*. Daunted by the prospect of their child being unwell and believing that they had acted as good parents by bringing their child to the department, the parents then felt that they had transgressed in some way. According to Neill & Coyne (2018), such criticism causes parents to question their status as a good parent, creating anxiety and hesitation when using health services in the future.

Having previously been reprimanded, the mother consequently expressed a sense of vulnerability at their attendance.

> *“I am a bit worried now about and what they [the HCPs] think of me. I’m feeling I might be over-reacting.”* **Mother – Interview 1**

Direct criticism was also experienced by a mother who, on a previous attendance was told by the doctor that she need not have brought her daughter to the hospital. After a few days, her child was no better and, not knowing what else to do, they returned. Acknowledging the pressures experienced by the NHS, the mother believed that she risked further criticism after ignoring the judgement from a health professional that their attendance was unnecessary.

> “*I don’t want to be seen to waste their [ED] time, especially after what the doctor said, that we shouldn’t have come last time, but I need to make sure we are not missing a serious problem.*” **Mother - Interview 12**

For this mother, an additional quandary was posed of either not doing enough for her sick child or being an unnecessary burden on emergency services; either option increasing her personal risk of criticism (O'Cathain et al., 2019). When people believe that they have done something that might lead others to form a negative judgment of their character or actions, they can experience feelings of devaluation, and weakening of their position and self-assurance (Leary, 2015). Yet the fear of a serious threat to her child, her sense of responsibility for the child's welfare, and a powerful drive to *"to make sure"* was able to overrule her emotional conflict and her personal risk of facing further disapproval.

First-time parents were particularly vulnerable to a disparaging HCP, learning that their inexperience signified that they were incompetent parents or that they were worrying needlessly. A mother and father spoke of the direct criticism received from the triage nurse for bringing their new baby to the emergency department and described feeling "patronised" as new parents, concerned for their baby and navigating the health system for the first time.

> *"I feel that we are judged as soon as you say we're first time parents. The triage nurse was a really patronising. She just said, 'he's brand new' and that he could 'just be seen by the GP'."* **Mother – Interview 4**

Such responses can create a conundrum since HCPs rely on parents to identify when their baby is unwell and to seek help accordingly. Instead of anticipating that a first-time parent might need more support, the HCP judged that as a result of inexperience the parents were unable to recognise accurately when their baby was sick, and was critical of their seeking help. Parents received the message that have acted wrongly or inappropriately, leaving them in doubt as to how they should have acted.

A study by Norman et al. (2016) observed the prevailing societal judgements held about new and young parents, the ensuing dismissal of their concerns by a HCP, and the dismay and anger felt by the parents in response. When questioned afterwards, the parents were able retrospectively to challenge the judgement of the HCP, but the impact on future care-seeking behaviour remained. Parents would weigh the risk of further criticism, the health of their child, and judgement on their parenting skills.

This mother appeared to accept the judgement from the HCP, but also defended her actions.

> *"I might be being a bit dramatic. But as he's only a 7-week-old baby, I'm prepared to be dramatic."* **Mother – Interview 4**

Not all criticism was explicitly said, nor was it unique to new parents. One mother of an older child commented on her discomfort whenever she had an appointment with the GP.

> *"I find him condescending, as if saying, 'she's back again'. That I'm worrying for nothing; wasting his time."* **Mother – Interview 14**

The mother did not elaborate how this was conveyed by the HCP but she described her relief when she felt listened to, and when her concerns were addressed. The response from the GP led her to feel that her concerns for her child were dismissed as not valid. She was apprehensive about seeking medical care, a problem recognised in previous studies when parents were hesitant to trouble their doctor if they had previously felt criticised or uncomfortable. Parents were unsure if it was acceptable to return to the GP if they continued to be concerned, their decision hindered by fear of criticism (Carter et al., 2020; Crampton & Wigley, 2017; Neill et al., 2016).

Neill & Coyne (2018) identified parental guilt and shame being induced by criticism from an authoritative figure such as a nurse or doctor. They point out the imbalance of power between a worried, vulnerable parent and the health professional. Fear of criticism can subsequently create additional anxiety around a future decision of when they should seek medical help, leading to a late consultation with serious consequences for the health of a child.

Indeed, one mother described how she had previously kept her unwell child at home for too long before bringing him to the hospital as she had not wanted to "*make a fuss*". Comparable to this mother, a study by Neill (2013) found that parents respond to an expectation that certain illnesses should be managed at home; this spares them receiving criticism from a HCP for seeking help for mild illness, and protects their moral character as a good and competent parent.

However, the mother conceded that her efforts to minimise any threat to her parental reputation meant that she failed to recognise the severity of how unwell her child was. When she eventually brought him to the emergency department, he was very sick and needed immediate treatment.

> *“I didn’t realise how ill he was. I felt terrible. I didn’t get it right that time.”*
> **Mother – Interview 3**

Sensitised to her response, she recognised that the need to protect her reputation from criticism was powerful enough to limit her ability to recognise the severity of her child’s illness. She no longer cared about what was thought about her. She put the needs of her child first and sought help much sooner, realising that her anxiety for her unwell child superseded any thought of what a HCP might think of her.

4.7 JUSTIFIED ATTENDANCE; exonerated by advice or past experience .

In contrast, some parents expressed no concern at being judged or criticised for their decision to attend the emergency department, believing their attendance to be correct and justified. A number of explanations thought to justify attendance were identified. These were a prior attendance at which reassurance was given and no censure was felt; previous experience of a very sick child and unwillingness to take risks with a new illness that might be as serious; confirmatory actions taken by the HCP in the emergency department; and being advised to attend by their GP or NHS111.

Notably, all the parents had previous experience of accessing urgent care at the emergency department. Several parents did not recall experiencing any sense of disapproval or criticism during their previous attendances, which perhaps offered confirmation that these were justified. Often parents will ask for reassurance directly from the HCP that they have acted appropriately, and, unwilling to offer any disapproval and upset an anxious parent further, the HCP will confirm that they have ‘done the right thing’ (Rowe et al. 2015).

> *I’ve always been told I’ve done the right thing when I’ve come to A&E. I’ve never been made to feel uncomfortable.* **Mother - Interview 16**

For some parents, their response reflected a new societal shift in mindset particularly for younger parents. Increasingly accustomed to instant gratification from technology and services, people are applying these expectations to healthcare (Holden et al., 2017). Indeed, a study exploring the views of younger parents found no indication of them being in awe of the HCP, instead seeing their demand for instant access to healthcare as their right (Norman et al., 2016).

Consequently, a number of parents seemed surprised when asked if they had any concerns about being made to feel like a worried parent. One mother shrugged and shook her head, replying, *“No, not at all”.* **Mother - Interview 10.** Another mother was confident that her decision was correct when she made a decision to seek help for her child, indifferent to the idea that she could be criticised for doing so. She was bemused when asked if she had any thoughts about being considered a worried parent and replied emphatically.

> ***“****I’m not worried about being a worried parent. I always feel justified in coming if he’s poorly. I’m not bothered.”* **Mother – Interview 19**

For some parents, there was an expectation that risks should not be taken with the health of a child which made them a priority for urgent medical care. A study by O'Cathain et al. (2019) found that parents were able to be more demanding in the interests of their child than they would be if they were seeking help for themselves. Carrying the responsibility for their child’s welfare led to an explicit sense of entitlement on the child’s behalf, which they believed was justified and deserving.

> *“If it were me, I’d wait, but not when it’s my baby. I feel like I have to get feisty to get heard. It’s the pushy that get through, but it shouldn’t have to be that way.”* ***Mother – Interview 33***

Neill et al. (2018) investigated the influencing variables that affected the parent’s response to fear of criticism. They found that parental confidence is greater when there is familiarity with the environment and processes, and relationship with the HCPs in which the balance of power has been equalised. One father was distinct from other parents, having already disclosed his profession in paediatric health. While earlier conceding his need for reassurance from another HCP, he also recognised the imbalance of power between a parent and a doctor having witnessed this from his own experience of being a HCP. He anticipated that receiving criticism might be an issue in the emergency department, but his paediatric knowledge permitted him to confidently question the authority of the doctor if he did not agree with the outcome.

> *“We feel justified when we come the A&E department. We feel confident in challenging the doctors so don’t feel worried.”* **Father – Interview 13**

Parents felt justified in bringing their child to the emergency department at a much earlier stage in the child’s illness if the child had previously been very unwell. This factor was instrumental for some parents in driving their need to seek help as soon as possible. Fear that their child might be developing a serious illness again caused parents to become overly cautious and anxious, lowering the tolerance of any risk to their child (McLauchlan et al., 2020; O'Cathain et al., 2019).

Three families described an occasion when they brought their child to the emergency department, and their child received urgent treatment for a serious infection. Separately, they articulated their worry that their child was beginning to display similar symptoms, and, not wanting to experience it again, they felt that their attendance was justified because of how unwell their child had been previously. On this occasion, the children were only mildly unwell. The parents anticipated that early intervention would prevent any further deterioration.

> *“He’s had sepsis before, and we were just worried.”* **Mother – Interview 5**

Often, it was the actions of the HCPs that confirmed to the parent that their decision to attend the emergency department was justified (Crampton & Wigley, 2017; Maguire et al., 2011). The practice of defensive medicine and the subsequent fear of stepping outside guidelines or protocols sees cautious clinicians initiate investigations and treat minor illness as potential symptoms of a more serious infection (O'Dowd, 2015). The child undergoes a thorough systematic examination or is kept in the department for a longer period of observation. Investigations such as blood tests are initiated shortly after arrival at the department, often instigated by nursing staff prior to a physical examination to expedite the patient journey, to keep within the 4-hour length of stay target, and to support a clinical decision to give treatment or discharge home.

One father explained how the actions of the HCP in the emergency department reinforced his decision to attend.

> *“We’ve always felt reassured when we’ve brought him to A&E. Feel he always gets fully checked over, and if he needs any investigations or anything, these can be done straight away.”* **Father – Interview 9**

The father went on to say how they had attended the emergency department on a number of previous occasions when the child was unwell with a similar illness. He commented critically that *"inappropriate attenders clog up the system"* but excluded himself from this concept.

> *"I'm not the worried parent, attending all the time. I know children will have minor bumps".* **Father – Interview 9**

Rejecting any thought that he might be considered an 'inappropriate attender", he believed that their previous attendances were appropriate and justified, likely reinforced by their positive experiences at the emergency department. The father felt able to recognise on behalf of others what is inappropriate, revealing how, without emotions clouding actions, an objective judgement can be made that others are responsible for the problem. Yet, parental anxiety for a sick child can bring a misaligned perception of urgency and appropriateness, lowering the threshold to seek advice and justifying attendance (Nicholson et al., 2020; O'Cathain et al., 2019).

Parents could justify their attendance if, on a previous occasion when their child was unwell, they had been instructed to attend the emergency department by another HCP.

> *"We've previously used NHS111, they advised us to come straight up, so we possibly cut out the middle-man."* **Father – Interview 15**
>
> *"I didn't ring NHS111. Think it would have been pointless as they would just tell me to come to A&E."* **Mother – Interview 16**

The parents were sceptical of what they perceived as wasting their time by needlessly seeking guidance, anticipating that the advice given would be the same. Seeing the GP service and NHS111 as an intermediary between the patient and the hospital, and seemingly unable to meet the needs of their child, they might as well *"cut out the middle-man"* and go straight to the emergency department. In doing so, they avoided waiting twice to access health care (Leyenaar et al., 2018; Nicholson et al., 2020).

Nonetheless, more than half the parents had sought advice and had been advised to attend by another HCP. This gave assurance to the parent that their attendance at the emergency department was justified, and, since they were absolved from making the decision and were following instructions, they were spared the prospect of any criticism.

> *"I always feel justified in coming as I get advice first. I've never just made the decision myself to come."* **Mother – Interview 12**

Perhaps because they were participating in this study and were questioned about their attendance at the emergency department, several parents wanted to clarify that they did not believe their attendance was warranted but felt they had no choice: they were obligated to follow the advice of the GP or NHS111. Parents perceived that there may be legal or moral consequences for not being seen to respond appropriately to the health needs of a child and disregarding advice (O'Cathain et al., 2019).

> *"We called NHS111, just for a bit of advice really. They called an ambulance to bring us here. We didn't really think that was necessary but felt we had to come as we've been told to come. No choice really."* **Parents – Interview 6**

One mother was confident in recognising tonsillitis and other mild illnesses and would normally make an appointment to see the GP. She had contacted the GP surgery, and, after describing her child's symptoms, she was advised to attend the emergency department. The mother considered that the illness was manageable by the GP but then had to act upon the advice, particularly as the GP would not examine her child in the surgery.

> *"She had to be seen by someone!"* **Mother – 21**

Another mother followed advice from her own mother and contacted NHS111. This service advised a GP consultation, but the surgery could not offer an appointment, so, in turn, they advised the mother to take her child to the emergency department.

> *"I thought it was a bit quick to come to A&E, but then thought I'd better come as I'd been told to."* **Mother – Interview 28**

As her child was discharged without needing any treatment, the mother was bemused at how the situation had escalated from asking her own mother's advice to being instructed to attend the emergency department when she would have been comfortable managing the child's illness at home.

GPs describe feeling less confident when dealing with small children, perhaps due to a lack of paediatric training or experience. Their threshold to refer a child to another service becomes lower when balancing the risk that the child might deteriorate more quickly than would an adult (Turbitt & Freed, 2016). Conlon et al. (2021) found that GPs report that they respond to pressure from parents to make a referral and will respect parent's wishes believing that this allows for parental participation in decision-making. Yet parents can choose to self-present to the emergency department do not need a GP to make a referral.

4.8 EXPECTATIONS OF THE ATTENDANCE;

After the decision had been made to attend the emergency department, parents were asked what they had expected would happen once they arrived. Naively, I anticipated that during their journey to the hospital parents would contemplate their expectations of their visit and what they predicted would happen. I had in mind to consider the process from booking in and being reviewed quickly, to being assessed and receiving treatment. As part of the study findings, I envisaged that this would uncover what kind of healthcare parents want to have immediately available and the aspects of care that parents perceive as being valuable when their child is unwell. Having established what parents want, I would apply such findings to inform future service design.

Similar to a study which explored parent's expectation and satisfaction of their attendance at the emergency department (Toma et al., 2009), it was found that the majority of parents had no initial expectations of their visit. Few parents were able to articulate any prospective notion of what their visit might entail, having not consciously given more thought beyond arriving in the emergency department and being 'seen' by the doctor. Parents assumed that they would receive some form of medical care but were vague in the detail of what this would entail.

> *"Don't know. Hadn't given it much thought. I suppose I thought he'd be checked over."* **Father – Interview 6**

A heightened state of anxiety may well overwhelm any thought other than getting their child to the hospital once the decision to attend has been made. Parents often describe a sense of immediate relief once they are in the emergency department, knowing that they are in the best place should their child deteriorate (Rowe et al., 2015). Yet, having hastened to the department to receive emergency care, several parents said they anticipated that they might to have to wait a long time. It is reasonable to suggest that the parents are able to recognise that their child's condition is not extremely serious and will not be deemed as requiring urgent attention by the HCP.

> *"Didn't really know what to expect. Probably that we would be waiting, but we were called through immediately. I suppose we thought he would be seen quickly in view of his age."* **Mother – Interview 4**
>
> *"I thought she would get triaged quickly in view of her age and red flags, but then I expected a long wait in the paediatric bit to be seen by a doctor."* **Mother – Interview 16**

The parent's limited ability to comment on their expectations specific to health care suggests that they are not always fully knowledgeable of the processes of how healthcare is delivered in the emergency department, but they are usually aware and are accepting that there may be long waits for treatment (Sangal et al., 2019).

Only three parents had a higher expectation of the quality of service by attending the emergency department.

> *"We've only had vague information off the GP. We're hoping for some answers and to know that we're not missing something."* **Mother – Interview 1**
>
> *"I expected a higher level of expertise because we're in the hospital."* **Father – Interview 4**
>
> *"I anticipated there would be someone here with paediatric knowledge to give good advice and make a decision."* **Father – Interview 13**

These parents expected to receive specialist knowledge that exceeded that of the GP. One mother (Interview 1) felt that she had exhausted the knowledge of the GP whose 'vague information' had conveyed to the parents that they were unable to diagnose their child's condition and subsequently unable to provide any reassurance.

Two parents had no expectations as they had intended to attend the co-located walk-in centre but had been re-directed to the emergency department.

> *“I thought we may have been seen a bit quicker, but I can see you’re busy. I’ve no other expectations as I’d planned to come to the walk-in centre.”*
> **Mother – Interview 7**

4.9 EXPERIENCES AND ENCOUNTERS

Often it is not the actions or words that people are able to recall but rather the feelings evoked by their memories of an experience. The famous American poet, memoirist, and civil rights activist Maya Angelou was reported to have said:

> *“I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”*
> Maya Angelou; American poet, memoirist, and civil rights activist (n.d. as cited in Tunstall, 2014)

While it was not possible to use parental expectations directly as a concept to lead future service design from this study, parents readily shared instances that had effectuated trust in the care of their child, This offered meaningful insight into the type of service that parents want to access when their child is unwell. Parents shared their experiences from past and present encounters with the health service and the impact this had on them personally as a parent when already feeling anxious and vulnerable.

Alongside those in the hospital setting, these included their experiences with their GP and in primary care. It is important for these to be included since the study was designed to investigate why children are brought to the emergency department with mild acute illness and if GP experiences hold some responsibility for driving attendance. Many themes blended together, and experience was often affected by a combination of events.

Several parents described the impact of communication on their experience and how this gave reassurance or reduced their confidence depending on an interaction that was verbalised or implied. A number of parents valued a dedicated paediatric environment and recognised certain actions displayed by the HCP that conveyed to the parents a sense of expertise. Many had a complex journey through the health care system before attending the emergency department, and this reduced trust and caused frustration.

4.9.1 Communication; feeling fobbed off and dismissed

Studies exploring patient satisfaction and perceived quality of care have established numerous times, that above all else, good interpersonal communication is the biggest contributor to achieving patient satisfaction (Abidova et al., 2020; Lacey et al., 2021; RCEM, 2015; Sonis et al., 2017; Toma et al., 2009). Specifically, parents recognised how the manner of communication influences their experience, trust and confidence significantly in the delivery of care (Woolfenden et al., 2000; Maguire et al., 2011; Neill & Coyne, 2018).

Having a sick child is already a stressful experience for parents, with additional anxiety and uncertainty over when to seek help. Feeling vulnerable, parents look to redress the power imbalance between the HCP and the parent by looking to the HCP for empathy and validation that they have made the right decision. The extra few minutes taken to communicate well ensures that the parent feels that they have had all their concerns heard and addressed, and that they feel reassured and equipped to manage their child's illness.

Yet good communication remains inconsistent and elusive as the parents described the difficulties that they experienced, referring to aspects of communication that left them doubting that their concerns had been heard or recognised.

> *"I want to be listened to properly*. *I've noticed, they'll* [the HCP] *pick up on one thing, like their increased breathing and just run with that. They don't listen to anything else, like about her ear pain*." She reiterated *"I had to keep going over the same detail to get the point across. He wasn't listening".* **Mother – Interview 11**
>
> *"I want to feel listened to and that my concerns are taken seriously."* **Mother – Interview 2**

One mother was perceptive about how communication had affected her experiences and gave an example of a previous visit to the emergency department when it was very busy and there was a long waiting time. When they were finally reviewed by the doctor, the mother described a rushed consultation.

> *"We were ushered out with no explanation for his illness other than 'he looks ok, come back if you're worried'. It's a much better experience when you feel*

> *listened to, when you don't feel like you're being rushed out."* **Mother – Interview 25**

The mother spoke of being particularly dissatisfied with this encounter. She felt that it was obvious that she was attending the emergency department because she was already worried, and this was emphasised by them choosing to wait a long time to be reviewed by the doctor. Yet she had received no reassurance, explanation or advice to help alleviate her worry or manage her child's illness.

Similar experiences were described by other parents who found it distressing when they perceived that their concerns were dismissed, or that they were wasting the time of the HCP.

> *"Whenever I see the GP with one of the children, I get the feeling they're thinking 'she's back again'. I'm made to feel like I'm worrying for nothing. It's always 'viral' so there's never any treatment offered. This means I'm back on the phone the next day to get another appointment as she's got worse. So, if she's no better, it's back to square one."* **Mother – Interview 14**

> *"I've taken the children to the GP and come out feeling dismissed with no treatment. The children did get better, so the GP was right, but I'd left the appointment still feeling worried and not knowing what else to do."* **Mother – Interview 18**

The statement from this mother exemplifies why effective communication is central to the experience of healthcare, since the mother conceded that the doctor had been right in the diagnosis, but her prevailing impression from the encounter was that she had been dismissed and left feeling unsure. Minutes given over to simply communicating well and sharing information about the expectations of the illness would provide parents with reassurance. Parents feel empowered to continue the care for their child and are less likely to leave the encounter still feeling anxious about their child's illness. Furthermore, the burden on future healthcare should be reduced as parents have a better idea of when it is appropriate to seek further help (Neill et al., 2013).

Indeed, several parents acknowledged that they would continue to seek medical help until they felt satisfied or reassured. The success of ensuring that parents do so depends heavily on the interpersonal ability of the HCP and how they communicate and impart information to the parent (Toma et al., 2009). It was recognised that experience was dependent on the individual practitioner's actions.

> *"After I came here last time, he was misdiagnosed so I took him to the children's hospital for another opinion, and they were really good. So next time he was poorly, I took him straight there, but it wasn't a good experience that time, so I've come back here, and it's been really good this time. I think it all depends on the person seeing your child."* **Mother – Interview 10**

Two mothers explained that they had previously had their concerns dismissed by a HCP when they were later confirmed to be justified. They responded by having a much lower threshold to return with their child for further assessment if not fully reassured on their initial visit to the HCP.

> *"I've not been listened to in the past, and I've been proven right. So now I just keep going back until I know it's sorted."* **Mother – Interview 2**
>
> *"I trust my own judgement as a parent. When he was a baby, he was passing blood. I kept going back to the GP, coming here to A&E until he was finally diagnosed with a dairy intolerance."* **Mother – Interview 23**

Parents experiences of being '*proven right*' reinforces their actions to continue to seek help until they were satisfied. It also reflects a deficit in service when professionals are rushing, not listening, not acknowledging concerns, and not giving information.

> "*Tell me he's ok and I'll go away, but if I'm not convinced, I'll come back."* **Mother – Interview 23**

Not all parents were able to challenge the health services should they feel that their request for help was obstructed by the attitude or response of the HCP. This mother described how her request for advice was ignored by her GP.

> *"I took her for her 8-week baby check, and I had an infection to my C-section scar, but the GP hardly glanced it. He didn't seem interested, but I didn't know what to do about it after that."* **Mother – Interview 28**

The mother had waited for the opportunity to ask for help and courageously exposed her surgical scar, but the mother's words suggest that she found herself embarrassed and dismissed by the GP who indicated that what was important to the mother was not important to the professional. The HCP is in a unique position of power as the vulnerable patient seeks their medical expertise but also their compassion and empathy. Yet it appears that the hierarchical power imbalance erroneously gives permission for the HCP to be rude and to ignore the patient, even failing to respect the patient as a fellow human being (Kee et al., 2018). This particular mother was left in a quandary as the HCP whom she relied upon to access healthcare and who had the power to help had refused to do so. She was still unsure if the wound needed treatment and for how long she should tolerate the infection and pain. She did not feel that she could go back to the GP but did know what else to do.

Several mothers spoke of being “fobbed off” when describing their experiences of seeking help from their GP. The use of this term implies that the parent’s concerns were not considered worthwhile and that the GP will say anything to placate them to make them leave.

> *“I feel the GP doesn’t listen. I get fobbed off.”* **Mother – Interview 7**
> *“If it’s a GP I don’t know, they just see me as a young mum who doesn’t know what they’re doing, and I get fobbed off.”* **Mother – Interview 11**.

A different mother recalled a conversation from a previous experience when in hospital with her young baby, who had been admitted with a respiratory illness and required treatment with oxygen. She expressed her worry for her child to the paediatric consultant who she then felt minimised her concerns.

> *“He said, ‘He’s not that unwell’. He was probably comparing him to other babies, but he was still poorly and needing oxygen. And we were worried about him.”* **Mother – Interview 25**

The conversation had a lasting impact on the mother, making her feel almost ridiculous for being worried. By failing to acknowledge the parent’s fears and in a poor attempt to reassure, the consultant implied to the parents that their concerns for their child were unwarranted (Bentley, 2005).

Parents were asked what created a sense of trust or confidence in the health professional when assessing their child. Without any difficulty, parents recognised the features of good communication and the impact that this had on their experience.

> *“We feel more confident when we feel listened to.”* **Father – Interview 15**

> *"I like to feel like I'm listened to, reassured. It's good communication when I'm given advice I can follow."* **Father – Interview 20**

One mother spoke of a particular GP at the surgery who the mother described as being "*really good*".

> "*They listen, spend time and examine you."* **Mother – Interview 16.**

Asking questions conveyed to parents that the HCP was interested and displayed expertise. Combined with a full examination of their child, this confirmed to the parent that the HCP sought to establish and address the problem.

> *"I feel confident if I'm asked enough questions, and the baby has a thorough examination, as then I feel the diagnosis will be appropriate."* **Mother – Interview 24**

One father reported that he thought that the HCP had asked all the right questions. He found this reassuring.

> "*She knew what she was doing*". **Father – Interview 13**

Similarly, a mother explained what conveyed to her a greater sense of confidence in the examination.

> *"Asking lots of questions and listening to answers."* **Mother – Interview 14**

The same mother expressed significantly greater satisfaction when accessing the advanced nurse practitioner at the GP surgery.

> "*She checks the heart rate, the temperature and oxygen levels. She examines her properly, whereas the GP will just look in the ears if I think she might have an ear infection. I'm not the expert, it might be the ears. But I like the fact that other things are considered."* **Mother – Interview 14**

Being 'seen' as well as heard was equally important as the failure to be acknowledged exacerbated the stress and anxiety that parents were already experiencing.

Parents explained that they were not always kept informed and were left waiting and unsure of what was happening next. There may have been an assumption by the

HCP that patients know what to expect when they attend the emergency department, or that the HCP did not have time to explain.

> *"I just want to feel that nursing staff are approachable, and they communicate what's happening. There's sometimes a lack of explanations of the processes. I don't know what we're waiting for next."* **Mother – Interview 11**

The mother conveyed her apprehension that, should she approach staff to ask, there would be a reproachful or dismissive reply. She would have preferred to be updated and informed routinely and spared the discomfort of being told that the staff are too busy or that there are long waits.

The parents of a young baby also described their distress at their perception and experience of poor communication. Having been awake most of the night waiting for an ambulance, they were exhausted, and after finally arriving in the emergency department they were allocated an enclosed cubicle with a door. After a prolonged wait in the cubicle and without receiving any further explanation of what would happen next, they described feeling ignored and abandoned.

> *"We've been shoved in a cubicle and no-one has come in to see us for about an hour. We heard a nurse say, 'it's been a long night' and then she left. She hasn't even spoken to us."* **Father – Interview 6**

The father's interpretation that they were 'shoved' into a cubicle suggests that they were put out of the way; unimportant and invisible to the staff. Overhearing the comment from the nurse who, focussed on going home at the end of a busy shift, reinforced a lack of empathy towards the parents and disinterest in their stressful situation.

A study by Bal et al. (2019) similarly found that parents reported problems with doctors and nurses failing to keep parents up to date and explain what was happening. The impact of the increasing demand on the care workforce is often poorer communication and relational care, and while parents will often acknowledge the difficulties faced by the HCP in their workplace, they still expect the HCP to contain their personal feelings and behave professionally (Bridges et al., 2019; Kee et al., 2018). Parents confirmed that communication is one of the most important aspects of care. A few moments of conversation and reassurance would satisfy most parents' need for prompt, kind and compassionate care (Maguire et al., 2011; Lacey et al., 2021).

4.9.2 Mixed Messages; "It was so inconsistent."

A further feature of good communication is clear, consistent information and advice (Peeler et al., 2019), yet several parents stressed that they had been given confusing information: initially information that implied the seriousness of their child's illness and escalated parental concern. Yet a subsequent delay to take action was at variance with the gravity of the initial message, leaving parents unsure of what to do, how to manage their worry, and care for their child. After contacting NHS111, one mother was told that her child needed an ambulance to take them to hospital. This impressed on the mother a sense of urgency in the situation, that her child needed rapid medical intervention. But then she was told that there was a two hour wait for the ambulance. The mother described the conflict in the message.

> *"I was getting mixed messages, telling us we had to go to hospital but then to wait two hours for the ambulance to come. I told them I would just take him in the car. I thought, if he needed to get to hospital because he was short of breath, surely it would be better to get him there as soon as possible!"* **Mother - Interview 19**

Similarly, after contacting NHS111, another mother was advised that an urgent telephone consultation with her GP would be arranged. The mother then experienced a wait of 6 hours before the GP called her.

> *"This was a very long time to be sat at home, waiting for a call when he's so unwell. I know I'm tired, but this was so stressful. They've told me they would ring me in the past and they didn't. I began to get worried they weren't going to ring again, and we'd been sat there wasting all this time for nothing."* **Mother - Interview 27**

She emphasised that she had to listen to the advice from NHS111 and to speak to the GP rather than just making her own decision to attend the emergency department. Wanting to be seen as a good parent by following the advice given, she did not feel that she could override this decision and risk any reproach when she was already feeling tired and stressed. Eventually, when the GP rang, they advised the mother to attend the emergency department. She described her annoyance at the delay when she could have taken the child earlier and he would have been reviewed much sooner.

> *"I knew the GP was just going to send us up anyway, but I had to wait for the call. Waiting a long time for the return phone call was hard."* **Mother - Interview 27**

The mother experienced an extended period of unnecessary distress caused by the uncertainty around waiting and receiving a telephone call, the perceived lack of control over the situation, and the lack of urgency after being informed that her child needed to be reviewed quickly by a GP. The child was examined in the emergency department, diagnosed with a mild acute illness, and discharged home. The family experienced a protracted and stressful journey through the system for a condition that was manageable in the primary care setting.

Another child had been taken back to the emergency department after being discharged from the hospital the previous day. The child was no better, and the mother told of her frustration at the "poor communication" and the "mixed messages" that she had received.

> *"I was told her bloods needed repeating, and then I was told by someone else that they didn't need repeating. No-one said why, but it was so inconsistent. We were told different reasons for why she was ill, and then we were just sent home."* **Mother – Interview 2**

The child continued to be unwell at home, and the mother was left in a quandary, with no clear diagnosis, and wondering if further blood tests would have helped to identify and treat the cause of the illness. The child was subsequently diagnosed with a simple urinary tract infection and commenced on treatment in the emergency department. The mother was conscious of the additional stress that she had experienced as a result of the conflicting information given from various health care professionals, their initial concern that the child was unwell enough to warrant blood tests, and their eventual dismissal without offering any clarity on the cause of her child's illness.

Her experience had caused her to lose confidence in a system that had failed to diagnose her child's illness, and in which conflicting information was given. The lack of clarity and mixed messages equally suggests to the parent that there is a problem with the knowledge and confidence of the HCP which, in turn, shapes the parent's perception of the quality of care received (Peeler et al., 2019).

4.9.3 Frustration; "I felt so angry and let down."

Wanting to access services appropriately, parents commonly reported their inability to make a timely appointment with their GP. Their failure to obtain an appointment exacerbated their anxiety, and several parents described their feelings of frustration at their attempts to access healthcare.

> *"I tried to get hold of the GP, but I was 29th in the queue so I gave up."* **Mother – Interview 28**

Poor access to the GP is a widely reported problem in previous studies (O'Cathain et al., 2019; Norman et al., 2016) which is then associated with increased used of emergency departments as parents, knowing that their child does not need emergency care, still requires an urgent review. There were reports of difficulty in navigating the GP surgery receptionist, with unsolicited advice being given. Similar to previous studies, the receptionists were seen as a barrier to accessing healthcare, (Conlon et al., 2021; Neill et al., 2016), and, preferring to avoid the battle, parents eventually seek alternative and more easily accessible routes into healthcare. A typical example was a mother who recounted a previous experience of her daughter being unwell with vomiting.

> *"I contacted the GP and was told by the receptionist that it didn't sound like my daughter was unwell enough to need an appointment. She got worse over the day, and we ended up coming to A&E in an ambulance. I felt so angry and let down by the practice. My husband complained to the surgery afterwards, and we haven't had any problems since."* **Mother – Interview 21**

A second mother also described the difficulties experienced with a GP receptionist on a previous occasion when her baby was unwell. The mother contacted the surgery and spoke to the receptionist who suggested that the baby was probably warm due to the hot weather. The mother rang the surgery again the next day and was able to speak to a GP who was very concerned about the fever in her two-month-old baby and the advice the receptionist had given. As fever in this age group can be an indication of a serious bacterial illness, the GP advised immediate attendance at the emergency department and the baby was admitted overnight. This affected the mother's confidence in navigating the GP system, and rather than face the conflict and the questions from the surgery, she found it less stressful to attend the emergency department directly.

> *"I don't like ringing the surgery. I prefer to come to A&E. I don't have to wait for an appointment. This is the best place."* **Mother – Interview 26**

During the COVID-19 pandemic when GP face-to-face appointments were limited, a different child had already been taken to see the GP who advised that if the child was no better in couple of days, to "*get her seen again*". The GP had not specified where, but when the mother tried to see the GP again on the day of the interview, the GP practice refused, advising her to attend the emergency department. The mother was baffled.

> "*The receptionist wouldn't give us an appointment. She said she's too young to be seen in the surgery. I think she's saying this because of COVID but we were seen by the GP the other day, so it doesn't make any sense."* **Mother – Interview 24**

Two families spoke of their frustration after being advised by NHS111 that their child needed to be seen by the GP and their subsequent difficulty in being able to secure an appointment. One mother was advised that her child needed to be seen within the hour, however there were no GP appointments available. The surgery advised contacting NHS111 again or taking her child to the emergency department.

> *"We were just being sent back and forth. It was ridiculous."* **Mother – Interview 1**

NHS111 correctly assessed that the child needed only a GP review, but this advice depended on GP appointments being available and it was left to the mother to arrange this. The GP was unable to accommodate their request which resulted in the family presenting to the emergency department, propelled by a sense of urgency that they had to be seen within the hour.

Similarly, a mother contacted NHS111 and was advised that her child needed a GP review within 2 hours. The mother anticipated that NHS111 would arrange this and she would be contacted by the GP surgery. When she failed to hear from the surgery, she contacted the surgery to find that no-one was aware that she was waiting for a telephone call. Since they had no appointments, the surgery advised her to take her child to the emergency department (Interview 23).

Parents were trying to access services appropriately but often found this challenging and problematic. It became clear why parents chose to self-present to the emergency department rather than to tackle a system that led to long waits, resistance from those meant to assist with access to healthcare, and poor communication.

4.9.4 A Complex Journey: The Parent's Story

Commonality of experience has been explored in the previous sections. This section focusses specifically on the complex and challenging journey that several parents experienced before reaching the emergency department having already experienced multiple contacts with the health service.

The parents of a young baby attended the emergency department as their baby had been unwell for the previous ten days, and she was experiencing intermittently high temperatures. They described her as being "*not her usual self*". They had taken the baby to see their GP on three separate occasions over the duration of the illness and told how each contact had reduced their confidence in the GP because the child was no better and the GP had not been able to establish a cause or offer reassurance.

> *"We've taken a urine sample in, which has been lost. The GP doesn't do any observations on her, and they can't tell us what's wrong."* **Father – Interview 1**

The father said that his worry for the baby was an infection that wasn't being treated and for any long-term implications that this might have for her. The mother explained that she just wanted her baby to be back to normal, and to be able to stop worrying. The parents had contacted NHS111 again that day and had been advised to seek a GP appointment within the hour. The GP surgery had no available appointments so advised the parents to contact NHS111 again or to attend the emergency department. The parents described their frustration as new parents trying to navigate the health system.

> *"We're just being sent back and forth."* **Father – Interview 1**

> *"We're being pushed onto the next person and no-one is giving us any answers."* **Mother – Interview 1**

The GP was unwilling to offer any further reassurance to the parents whose baby did not have any typical signs of a serious illness or infection, and a cause that would reassure the parents could not be established. The parents repeatedly sought help until the GP, out of options, advised them to attend the emergency department. Here, the baby would be assessed by a different HCP, investigations could be initiated easily, and paediatric expertise was more readily accessible.

The experience of the parents typified the findings of Neill et al. (2016) who established that parents will lose confidence in the HCP when they fail to make a diagnosis, when there is ineffective treatment, when conflicting information is given, and when the HCP continually refers the patient on to others. The parents wanted to ensure that nothing was being missed and were hoping for answers, placing the burden of responsibility on to the emergency department to meet the need for reassurance for a non-urgent illness.

Another child had been taken to see the GP two days prior to attending the emergency department and was referred directly to the Children's Observations and Assessment Unit (O&A) for examination by the paediatric team. Observation and Assessment Units are hospital-based short stay facilities for children with acute illness, providing monitoring and treatment for a period of up to 24 hours (RCPCH, 2017). On discharge, the O&A can offer an open-access service to families. Should the child remain unwell, parents can make contact with the unit and return with their child for further assessment. The mother had utilised the open access provision the following day and was subsequently discharged for the second time.

However, she remained worried that her child was still not getting better and explained that she had contacted the O&A for the third time. On this occasion, she was advised that she had exceeded the 24-hour period by one hour and would have to attend the emergency department. She expressed her reasons for continuing to seek medical help. She doubted the information that she had been given so far and believed that the medical team was 'missing something'. The child had a medical history of recurrent tonsillitis and was awaiting a tonsillectomy, they had completed a course of antibiotics just prior to becoming unwell again. The mother felt that the medical team had remained focussed on a diagnosis of yet another upper respiratory tract illness without considering any other source of infection. Her doubts over the diagnosis were justified when investigations initiated in the emergency department confirmed that the child had a treatable urinary tract infection and she was discharged home with a course of antibiotics.

The mother described herself as being exhausted by the process that she had experienced which ultimately led to her visit to the emergency department. Her child had been discharged twice from the O&A and was refused access a third time. (Later, she received an apology.) She concluded that her child had been misdiagnosed from the beginning and that her concerns had been ignored.

> *“They didn’t look at her with fresh eyes. They just thought it was the same illness as before. It’s only because of my persistence as a mum who knows my child.”* **Mother – Interview 2**

She told of the anxiety generated from being told conflicting plans for management of care, and of poor communication between the doctors. She was further frustrated at having to return to the emergency department to secure the help that she needed, and was upset that she had almost missed her older child’s first day at school because of having to return to the hospital repeatedly until her child received the correct diagnosis and treatment.

When asked what she would do in the future, she said that she would feel confident in assessing the severity of illness and know which service to access.

> *“If it’s minor or I already know the diagnosis, I’ll go to the GP. If I feel it’s too complicated for the GP, I’ll come to A&E.”* **Mother – Interview 2**

This experience emphasised her need to feel that her concerns were taken seriously, that she was listened to, and that her concerns were not dismissed. She concluded that *‘I know my children’*. After her protracted experiences of dealing with the GP, O&A and the emergency department, she confirmed that the service that she would like to access when her child is unwell should offer high standards and consistency of care across elements of the services with improved communication.

A mother of a 14-year-old girl described how her daughter had suffered with intermittent abdominal pain for the previous four weeks. She had taken her daughter to see the GP on three occasions, and on the first time she was prescribed antibiotics to treat a urinary tract infection. Her pain did not resolve so she was advised by the GP to attend the emergency department where bloods tests were taken. The results were normal, and the mother was told by the examining doctor that they probably did not need to attend the emergency department. It was suggested by the doctor that there could be a gynaecology cause of the pain and that the GP should refer to the gynaecology speciality. The mother returned with her daughter to see the GP as instructed by the emergency department doctor. The GP felt that a referral to the speciality was not warranted at that time, and instead decided to instigate further investigations, though not immediately. Five days after the last GP consultation, the mother was increasingly worried that her daughter was no better and there was no explanation for the pain. Her daughter was missing school, staying in bed, and starting to feel very low in her mood. The mother contacted NHS111 again for advice. The service suggested that she should make an appointment with the GP, who advised the mother to return again with her daughter to the emergency department.

> *"I'm really hoping she can have some more investigations today if this is the next step in getting a diagnosis. I don't know how long we can keep waiting when she's still poorly and missing school. I am worried, though, after the doctor said last time that we shouldn't have come. I don't want to waste their time. I know everyone is busy, and I don't want to waste resources. But the GP told us to come, and I don't know what else to do."* **Mother – Interview 12**

It was difficult for the mother to wait for an undetermined time when her daughter continued to have symptoms that were affecting her daily life significantly, and there appeared to be little sense of urgency to establish the underlying cause. Her relief from worry was at the mercy of the GP and arrangement of future investigations.

Taking into consideration the length of time for which her daughter had been unwell and the multiple contacts with the health services, it was understandable that the mother was no longer able to trust a system in which clinicians gave conflicting information. Yet she responded to the unequal power perceived in the relationship between the HCP and the parent by feeling vulnerable to criticism for continuing to seek help (Neill et al., 2014). A study by Carter et al. (2020) confirmed that parents were often unsure of the acceptability of returning to their GP for a further review should they continue to be concerned, having already felt criticised or dismissed. Yet they found that when parents returned with their child, it signified that they have persistent concerns that are not always acknowledged by the HCP, and that ignoring valid parental concern can delay timely referrals to a health specialist. On this final visit to the emergency department, the child was diagnosed with constipation, a condition recognisable and manageable in the primary care setting. The mother was relieved that a treatable cause for the pain had been established but was incredulous that they had waited so long for a common problem to be diagnosed.

In a different case, the mother of 9-month-old baby was clearly frustrated. The previous day, she had had a telephone consultation with the family GP as her child had developed cough and cold symptoms. The GP decided that a face-to-face appointment was not necessary but advised the mother to contact the surgery again should the child become more unwell. By early evening, the baby appeared to be short of breath so the mother contacted NHS111 for advice, anticipating they would make her an out-of-hours appointment with a GP service.

> *"From what I must have explained to her, they surprised me and said he needs an ambulance."* **Mother – Interview 33**

The family waited two hours for an ambulance, and they were taken to their local district general hospital, a different hospital to the one in this study. The mother reported that they were triaged, but as the department was very busy, they then sat on the floor of a busy waiting room for a further two hours before a nurse announced there was still a seven hour wait for patients to be seen. The mother described her reaction.

> *"I thought, this was ridiculous. We didn't even need to be there. I just wanted someone to listen to his chest."* **Mother – Interview 33**

The mother spoke to a nurse, who briefly assessed the child, and confirmed it was safe to take the child home and make an appointment to see the GP the following morning. The next day, the mother contacted the GP surgery again, but they would not offer an appointment and advised that she should return with the child to the emergency department. They waited a further three hours in the department before the baby was diagnosed with a respiratory illness and discharged home.

> *"All this could have been prevented. We didn't need a blue light ambulance, only to then be told there was a seven hour wait. We've sat here for another three hours today. All I wanted was the GP to listen to his chest. We didn't*

> *need to have all this. They could have done this in a few minutes.”* **Mother – Interview 33**

While many parents are questioned for their attendance at the emergency department, and the case judged as ‘an inappropriate attendance” or “clinically unnecessary” (O’Cathain et al., 2019; Nicholson et al. 2020; Simpson et al., 2021), the stories of these families show that the journey to the emergency department is often complex and far from being driven by a simple decision to attend. Already worried about their child, parents often experience a stressful navigation through the health system (Nicholson et al., 2020). For these and many other families, this could have been avoided if care had been easily accessible and delivered correctly at the start of their journey. Their stories emphasise that health services are not currently in place to provide children and families with easily accessible healthcare and a high standard of paediatric expertise to meet the health needs of children adequately and to support parents to continue with their ongoing care.

4.10 WHAT PARENTS WANT

After describing their journey and their experiences, parents were asked what kind of health provision they would like to be available when their child was similarly unwell. Not all parents were able to offer a clear definition of what their ideal health service would look like, but they could describe features of their encounters with healthcare that they valued. For parents who were able to offer service suggestions, it was evident that rapid access to healthcare was important when parents were worried about their child and they did not feel able to wait for a long time. This is not a new phenomenon. The Royal College of Emergency Medicine (RCEM, 2015) reported a reluctance to wait when care needs were perceived as being urgent by the parent or patient and the resulting burden placed on emergency departments, yet little has changed to facilitate rapid access to healthcare.

Parents also wanted to feel confident in the expertise of the HCP and satisfied with the consultation. Equally they wanted the HCP to allow time for their concerns to be heard and acknowledged. They preferred an environment designed around the needs of the family which also conveyed confidence that it included paediatric expertise.

4.10.1 Instant Access; "I don't want to wait when my child is unwell."

Families described how difficult they found waiting to access health care when their child was unwell. Delays in accessing care were intolerable after the parent had made the decision that their child needed urgent care. Waiting was seen to prolong the suffering of the child and the anxiety of the parent (Bentley, 2005; Byczkowski et al., 2013; Peeler et al., 2019).

> *"I was worried about him. I don't want to wait when my child is unwell."* **Mother – Interview 26**

Several parents referred to difficulties in getting an urgent appointment to see their GP and explained why they chose to attend the emergency department.

> *"Because the baby can't tell you how they are feeling, I feel like I need rapid access to a service that can assess and reassure, but I often can't get an appointment with my GP*." **Mother – Interview 16**
>
> *"The GP was unavailable, and I wasn't happy to leave him any longer to wait to be seen. There's always access to healthcare at A&E."* **Mother – Interview 23**

One father, a frequent user of the emergency department, acknowledged that people will rush with their child to the easiest service to access.

> *"I am happy with the way things work. If we think he needs to get seen, it's a quicker service to bring him to A&E."* **Father – Interview 9**

A mother described how stressful she found it when trying to access healthcare urgently. Waiting exacerbated her anxiety as she worried that her child was at risk of deteriorating during the delay in getting through to the GP surgery. It made sense to her to bring her child to the emergency department, knowing that she didn't have to fight to get an appointment, and the child would definitely receive healthcare. Yet she recognised that attending the department was still not an ideal service, and she would prefer an urgent appointment system which could offer same-day appointments.

> *"When I'm trying to urgently access the GP, it takes continual calls or queuing for long periods to try and get an appointment only to be told to try again the next day. This is very frustrating and stressful when you're waiting, and you're*

> *worried about your sick child, only to be told there's no appointments and you're desperate to have your child seen."* **Mother – Interview 14**

One mother expressed her frustration with healthcare services but was distinct from other parents in her purpose for wanting rapid access to healthcare and treatment. From multiple health encounters, she had experience of various urgent care processes and explained that she wanted a service that would fit around her lifestyle of working and having two small children. The mother was honest about the pressure she experienced when her child was unwell and the significant risk to her employment. Despite this being the only mother in the study to make reference to caring for children and balancing work commitments, it is likely to be the reality for many parents. Neill et al. (2016) highlighted the difficulties experienced by parents in securing a GP consultation around the busiest times in the family day which lead to parents accessing alternative but more convenient routes into healthcare. She sensed a reluctance in practitioners to prescribe antibiotics for what might be considered a self-limiting infection, but then believed that her child was refused treatment that was needed. As a result, she believed that the illness would be prolonged (which she was desperate to avoid), and she would have to spend even more time accessing healthcare again. She found this frustrating.

> *"I need the treatment due to my lifestyle. I can't keep taking time off work every time they're ill. The diagnosis of a viral illness is an excuse not to treat my child until she deteriorates when she's given antibiotics."* **Mother – Interview 11**

After describing her difficulty today in getting the doctor to listen to her and "*getting her point across*", she was eventually satisfied with her visit to the emergency department when her child was prescribed antibiotics.

The mother was not prepared to wait for her child to get better without intervention, nor to risk her child becoming more unwell and having to repeat the arduous process of seeking further help. Instead, she fought for active treatment at the early stage of the illness. This relieved her stress of waiting as she felt that something was being done to make her child recover rapidly and she could hope to avoid more time off work. When there are consequences of the child's illness on the normal functions of daily life, the degree of disruption becomes a significant trigger for help-seeking (O'Cathain et al., 2019). For this mother, the stress of the interference with her employment appeared to be greater than the stress caused by her child's health, revealing the impact of even mild illness on the functions of a family's everyday living. She stated that she would prefer a simple and easily accessible service to be available when her children are unwell, instead of navigating around the GP, the walk-in centre and NHS111 which she found time-consuming and draining.

> *"It would make life so much easier to have just the one place to come to when kids are unwell."* **Mother – Interview 11**

4.10.1 Expertise; "I prefer to come to A&E as you're guaranteed to get seen and sorted."

Similar to the findings of previous studies (Costet & Wong et al., 2015; Lacey et al., 2021). Several parents anticipated that medical staff in the hospital would have superior knowledge and skill to the HCP in primary care. This may have been reinforced following a previous positive experience of the emergency department, or because the parent had been advised to attend by their GP. This advice seemed to convey the message to the parent that the GP could no longer manage their child's illness.

> *"I expected a higher level of expertise because we're in the hospital now."* **Father – Interview 4**

> *"The doctors in A&E are more specialised and used to seeing children with similar symptoms."* **Mother – Interview 16**

The second mother interviewed believed that the GP could only manage an illness that she herself was able to identify, and she would access the GP service only to obtain treatment. Should she not recognise the source of illness, she assumed that the HCP in the emergency department would have the expertise and ability to diagnose an illness less clear in its origin.

> *"If I'm confident I already know what the problem is, I would go to the GP. However, if I was unsure, I would come to A&E."* **Mother – Interview *2***

Parents spoke of the actions undertaken by the HCP once the child was in the emergency department that conveyed a level of expertise.

> *"We always feel reassured when we've brought him to A&E. He always gets fully checked over."* **Father – Interview 9**

> *"You get a quick and full assessment in A&E. Apart from the distance, I prefer to come to A&E as you're guaranteed to get seen and sorted."* **Mother – Interview 8**

Parents valued a thorough examination of their child that conveyed that everything was being considered and nothing would be missed, finding this more reassuring than an examination that focused only on the presenting symptom. This was more difficult to achieve in primary care where time constraints imposed on GPs led to parents feeling that the appointment and the examination of their child was rushed (Rowe et al*.,* 2015). Several parents compared their GP experience with the care they received in the emergency department where there was often more time to perform a comprehensive assessment and observe the patient for a longer period.

> *"At A&E, its' a more thorough experience. He gets his ears checked and throat checked, whereas if I said to the doctor, "I think he has urine infection", he would just look at that."* **Mother – Interview 29**

Holden *et al.* (2017) expressed concerns that performing unduly thorough examinations for a mild acute illness raised parental expectations and reinforced the need to attend the emergency department. However, parents in this study were clear that a thorough examination was what they wanted to reassure them that nothing about their child's illness was missed. Moreover, parents felt satisfied that this could be undertaken by their GP if they allowed more time for the consultation. The actions performed by HCP that conveyed expertise were not witnessed consistently in the emergency department, and parents could equally give examples of expert care received from their GP. Experience of various services was enough for one mother to recognise that the quality of care was dependant on the clinician examining her child rather than the location.

> *"It depends on the person seeing my child, wherever they are seen."* **Mother – Interview 10**

Parents valued the clinician consulting colleagues and seeking guidance about the management of their child. This offered further reassurance that the examination was comprehensive and there was a consensus of expert opinion: the outcome was validated, and this generated trust.

> *"We saw lots of different doctors, 2nd and 3rd opinions. I found this reassuring and liked that there was easy access to specialists."* **Mother – Interview 3**

Taking time to explain to the parents, and offering clear advice and information conveyed expertise, increasing parents' confidence in the consultation. When information was vague and left the parent feeling unclear, it caused parents to think that the clinician did not know, either.

> *"I think good communication instils confidence, a thorough examination, good listening skills, and then information giving."* **Father – Interview 13**

> *"I trust someone more if they've good listening skills and give good explanations."* **Mother – Interview 11**

Whereas some aspects of attending the emergency department conveyed a higher level of knowledge and skill, overall it was time constraints which limited the quality of the examination and communication. This was most often experienced when seeing the GP, and this had the greatest impact on the parent's perception of expertise.

4.10.2 A Dedicated Paediatric Environment

Attention to the psychological needs of parents and carers is an integral part of healthcare for their children. If the environment is specifically designed for children, the impression given is that care is multi-faceted yet specialised as it presents a child-friendly attitude and paediatric expertise. It includes the needs of the parents and understands a child's need for play (Peeler et al., 2019). Accordingly, parents expressed their preference for an area dedicated to reviewing children that is separated from adult patients, also concerned that their child may be exposed to distressing sights and sounds without anyone safeguarding or filtering the experience.

> *"My heart sank when I saw the walk-in centre had moved to A&E. I was worried we might be sent there instead, and she'd have to wait with adults when she's in so much pain. I would have brought her during the night, but I didn't want to get seen in the adult area. Being sat in the adult waiting room is very inappropriate for a child, especially if you're waiting for a long time."* **Mother - Interview 11**

For one father, providing a separate paediatric area conveyed a higher level of authority in caring for unwell children.

> *"I think being seen in the paediatric area is better. It's designed for children, so we feel like we are being seen by specialists in paediatrics."* **Father – Interview 13**

Parents recognised when staff were trained and competent in the specific health needs of children who also understood and supported the needs of the parent.

> *"The staff engage and seem to care. They're more involved in caring and offering support, like they want to participate and reassure."* **Mother – Interview 23**

A mother who brought her baby to the emergency department twice within a few hours compared two very different experiences of being cared for in both the adult and the paediatric areas. Her first visit was during the night when the paediatric area was closed, and the family was cared for and discharged home from the adult department. The mother described how she did not receive the clear guidance from the emergency department doctor that she had sought.

> *"I just didn't feel confident in what he was telling me. I didn't really get any answers: he didn't seem to know."* **Mother – Interview 30**

She remained fearful that her child might have a serious illness and so returned to the emergency department the following morning. This time, the child was cared for in the paediatric area by paediatric nurses and an enthusiastic junior doctor. The mother commented how the staff were *"much better with him"* which reassured her that the assessment was likely to be more accurate and thorough. She observed how the doctor sought the opinion of senior colleagues and the child was subsequently given a diagnosis which provided her with a clearer understanding of the illness and management.

> *"I feel much happier now. I know what I'm dealing with. It's sorted."* **Mother – Interview 30**

Parents referred to the superior equipment in the emergency department, perhaps believing that this would be more comprehensive or accurate, but also inferring that the availability of up-to date health technology ensures the availability of up-to date clinical practice and knowledge.

> *"I'd always seek advice, try and see the GP or whatever, before coming to the A&E, but here's better. The equipment is better, and you can do investigations."* **Mother – Interview 12**

Parents valued the access to diagnostic tests and investigations that were more easily available in the paediatric emergency department and several parents spoke of their relief when investigations were initiated shortly after their arrival. These were generally the parents of children who had been unwell for a few days, or in whom the parent thought there may be a serious bacterial infection. The parents' response to the uncertainty of their child's illness typically reflect the findings from the study by O'Cathain et al. (2019) as they explored patient decision-making. When there is doubt around the symptoms, the symptoms last longer than expected, or do not improve or worsen, the risk of serious illness is perceived as greater and drives the need to access resources and expertise rapidly to establish a cause. Parents felt grateful that they did not have overcome a reluctance in the HCP for tests to be initiated which might clarify the diagnosis.

> *"I was hoping some investigations would be done, taking her blood and checking her urine. I was really relieved when the nurse did the blood tests. I thought I would really have to push for something to be done."* **Mother – Interview 2**

> *"I was really worried about her so when they checked her bloods after we got here, I felt relieved, like I was listened to. The results came back alright, so that's peace of mind."* **Mother – Interview 16**

A father summarised the benefits that he had observed from bringing his child to be reviewed in the paediatric emergency department.

> *"It's a good experience for parents and children as they are seen in a paediatric area by lots of staff. The children can be fully assessed: all the heart rate and temperature are recorded etc. There's more time to look after them. If he needs any investigations or anything, these can be done straight away."* **Father – Interview 9**

Not all parents described a positive experience in the paediatric emergency department, however. Since there was little control over the numbers of children attending the department, the area could rapidly experience the pressures of running out of space and an overwhelming workload. This heightened parental stress as there was nowhere to wait comfortably, communication was reduced, care delivery was slow and consultations were rushed Several parents commented on the impact that they felt this had on their experience and the care their child received.

> *"I've seen how busy it gets, and staff weren't checking the children. There was no time to give any care. It's too small for the numbers of people that were there, and there wasn't enough staff."* **Mother – Interview 25**

Furthermore, the effects of a crowded environment are a lack of privacy and dignity when being examined and treated. Confidentiality is particularly important when considering any safeguarding aspects of care (Bal et al., 2019).

4.10.3 Time for the Consultation; "It all felt very rushed…it was such a waste of time."

The study found that parents judged the quality of their experience by their perception of the behaviour of the HCP. The ability of the HCP to convince the parent of their competence depended on their attitude towards the patient or parent, their communication style, and ability to demonstrate that they cared. In a busy environment, it appeared that time was not necessarily measured in minutes but by the quality of the interaction. This is recognised in the work by Kuhn (n.d.) who considers it is the actions of the HCP that work to convey a sense of time for the patient (or parent) and transpire as the fundamental determinant to demonstrating care and achieving patient satisfaction

Time to care was a theme that emerged after a several parents described the impact of being rushed through the consultation, often after waiting for a long time. Their concerns were rapidly rejected with no further answers or information given.

> *"When we finally saw the doctor it all felt very rushed. We were rushed out, and we still didn't know what the problem was. It was such a waste of time."*
> **Mother – Interview 25**

> *"It felt very rushed, and she was misdiagnosed. I came out feeling pretty frustrated and upset. I didn't know what else to do."* **Mother – Interview 22**

At a baby's 6-week check-up, a GP told the mother that he could hear a heart murmur. He asked the mother if her child had previously been diagnosed with a murmur to which the mother replied that she had not. She anticipated that he would explain further, but he did not, instead writing in the child's medical records that everything was satisfactory on examination of the baby. The mother did not say why she did not challenge the doctor at the time. It was after leaving the surgery that the mother reflected on the consultation, alarmed that the GP had implied that he had found a problem with her baby's heart. The mother felt that he had ignored his findings as, recognising that he was busy, this would take him time to address. She was waiting for another urgent appointment with the GP, unsure if her baby had a heart murmur, and worried about the seriousness and implications this might hold for the health of her child.

> *"The GP is rushed and busy. He's the only GP at the practice and trying to manage all the patients. I think he cuts corners."* **Mother – Interview 7**

In contrast however, another mother was able to describe an experience which led her to feel that the GP offered a good service, almost surprised at their demonstration of care. After having a telephone consultation with her GP, the GP took the time unexpectedly to ring the mother the following day to see how her child was.

> *"I thought this was really good, like they cared."* **Mother – Interview 24**

As well as taking the time, parents wanted to feel that the HCP was meaningfully and relationally engaged with them by recognising the significance of their role as a parent and their child as an individual. In the emergency care setting, relationships are often transient, and there is a risk that the child is not referred to by their name, but parents will overhear the HCP refer to the "D&V in bed 5". To the listening parent, the child and family are anonymised and dismissed as not being important enough for the HCP to learn their name. Inequality of power in the relationship between the parent and the HCP is maintained (Neill et al., 2018). Significantly, Emmamally et al. (2020) found that when interacting with a HCP parents' perceptions of care are based on what they see and hear.

In this study, parents related how they wanted it acknowledged that they have expert knowledge of their child but are seeking expert knowledge of an illness.

> *"Parents know their child. They know the symptoms, but don't know the cure."* **Mother - Interview 34**
>
> *"I want to feel listened to and that my concerns are taken seriously. I know my child."* **Mother – Interview 2**

Ertmann et al. (2011) recognised the importance of acknowledging the parents strong emotional response that they may have to their child's illness. Parents wanted their child to be recognised not as a symptom or an illness but as being most precious to the parent and deserving of treatment as a unique individual.

> *"I know that health staff must see lots of unwell babies and children – but this is my child."* **Mother – Interview 6**
>
> *"I would like him to be treated like a child, not just a symptom."* **Mother – Interview 29**

These were powerful observations from mothers, signifying that the needs as a child were greater than the illness that brought them to the emergency department. Practitioners were observed to focus only on addressing symptoms and overlooking the need for care to encompass and acknowledge a small child who may need specific gentle and age-appropriate encouragement to comply with the examination and treatments. A different mother, when asked what she wanted from her consultation with a health service, replied, *"I don't want to be dismissed. I don't want to have to fight. It's often the small things like caring for me, too. It's the kindness shown."* **(Interview 35)** Similar to the findings of Byczkowski et al. (2013), parents confirmed that what they wanted from the HCP is to feel cared for.

4.11 CONCLUSION OF FINDINGS

The aim of this study was to explore how parents arrived at their decision to attend the emergency department. The reasons behind their attendance were shown to be complex and multi-faceted but with many commonalities. The majority of parents had sought advice prior to their attendance and more than half of the participants were advised to take their child by another HCP. Parents responded to their worry and sense of responsibility for the wellbeing of their child but were also aware of the pressures on the health service and attempted to access the services appropriately. They became frustrated with a system that meant long waits or referrals around the various services to get a medical assessment for their child. Many parents spoke of feeling dismissed by the HCP with little reassurance or information given about the ongoing care of their child. This led to them returning to services to seek further help to manage their child’s illness.

As parents shared their experiences, it became clear what type of health service they would like to have available when their child is unwell.

The message from parents was that expertise was conveyed by the HCP when time was allocated to care, to listen, to explain, and to address the parent’s concerns. Likewise, for the HCP to consider the child and parent compassionately as people in need, rather than as an isolated symptom requiring treatment. While factors such as a child-friendly environment were welcomed, pressures placed on the HCP to meet targets or to deal with building acuity led to consultations being rushed. This had a detrimental effect on the quality of communication and families felt dismissed, uninformed and unimportant. The study subsequently highlighted the continued imbalance of power felt by the parent when relating to the HCP.

The RCPCH have devised standards for the emergency department, emphasising the provision of a suitable child-friendly environment and staff appropriately trained to care for children (RCPCH, 2018a). Alongside the standards, the RCPCH have devised an audit tool for the emergency department that is driving improvements, making each hospital accountable for the standards of paediatric service provided. The RCPCH have similarly issued guidance to general practice that places importance on the GPs educational needs, achieving a correct diagnosis, and their ability to access paediatric specialisms (RCPCH 2018b). There is a marked difference in the expectations from the RCPCH for two services that provide similar care for children. The emergency departments are responding more holistically to the needs of the family. Parents are perhaps reacting to the improvements, valuing the availability, the expertise and the environment, and making the emergency department their preferred option.

4.12 TELEPHONE INTERVIEWS

It was intended that the original interview would be followed by a telephone interview 2-3 days later once the family had had opportunity to reflect on their experience in the emergency department. The first 16 interviews were carried out immediately prior to the start of the COVID-19 pandemic and from these, 7 telephone interviews were completed. Two attempts were made to contact the families after their visit as agreed in the patient consent form, and if the family could not be contacted, only the data from the initial interview could be included. It was observed that the data from the telephone calls did not add significantly to the data collected in the initial interview. It had already been established that parents had few expectations after their decision to attend the emergency department, so the telephone follow-up could not show if their expectations had been met. Parents reiterated their previous and most recent experiences and from these, many were able to articulate the type of service that they would like to be available when their child is unwell, which remained the overall purpose of this study.

There was a further practical consideration in not pursuing further telephone follow-up calls. Parents had been informed in the study consent form that they would receive a telephone call via the hospital telephone number. Following the onset of the COVID-19 pandemic, it was not considered appropriate or necessary for the researcher to attend the hospital solely for the purpose of completing telephone interviews.

4.13 THE IMPACT OF COVID-19 PANDEMIC AND HELP SEEKING

The data collection was affected by the outbreak of the COVID-19 pandemic which saw restrictions such as school closures and social distancing measures imposed in an effort to prevent the spread of infection. The restrictions also reduced the spread of common childhood infections, and the threshold to attend the emergency department appeared to rise as people avoided visits to the hospital, concerned that they might be exposed to the COVID-19 virus or not wishing to increase the burden on the hospital. As a result, paediatric attendance at emergency departments dropped by 62% within the first few months of the pandemic (McConkey et al., 2021). Initially, there was concern that some children were being kept at home with a serious illness requiring treatment who would eventually attend the hospital in a much more serious state of need, but few sick children were found to experience a delay in presentation (Roland et al., 2020).

Indeed, this study found that parents were able identify the risk that their child had a serious illness which overcame the fear of exposure to COVID-19.

> *"Children die from meningitis but don't seem to be getting poorly with COVID. I couldn't take the risk. The coronavirus then didn't bother me then. I just needed reassurance this wasn't a serious illness for my child."* **Mother – Interview 17**
>
> *"I was a bit anxious about coming to the hospital because of COVID, but I was more worried about the rash and needed to rule out meningitis. I was aware of the need for speed and that she would have to be treated quickly."* **Mother – Interview 18**

Writers on the phenomenon wondered if the drop in attendance represented a change in parental behaviour (Isba et al., 2020) and therefore an opportunity to continue to educate parents on their help-seeking behaviour and 'inappropriate' attendance at the emergency department (Scaramuzza et al., 2020). Yet, as restrictions eased and children returned to school, the number of children attending the emergency department began to rise again. Data collection continued and parents related their response to the pandemic and how this influenced their help-seeking behaviour.

It was evident from speaking to parents that children had suffered fewer episodes of illness during the pandemic restrictions, and no parent described experiencing any pressure to try to manage an illness without seeking help. To reduce the risk of transmission, patients had been accessing the GP service in new ways. 'Face-to-face' patient contact was avoided and replaced by telephone or video consultation, and by sending images of, for example, rashes into the surgery for the GP to see. Some parents found that this was useful, however a number felt that their child needed to be examined physically and subsequently brought their child to the emergency department. One father explained that he received reassurance from an out of hours GP telephone consultation but did not follow the advice to contact the GP again the next morning.

> *“I didn’t feel another telephone consultation would be useful. I needed someone to look at him properly, to listen to his chest. You can’t do that over the telephone. That’s why I’ve come here.”* **Father – Interview 20**

> *“He had a rash and they [the GP] asked for photos, and I spoke to them on the telephone. They said they thought it was hand, foot and mouth, but I thought, how can you diagnose what a rash is on a baby just by looking at a picture? So, I ended up taking him to A&E anyway – how would they know it wasn’t meningitis?”* **Mother – Interview 33**

Despite varying levels of satisfaction at how patients received healthcare during this period, an opportunity to change how people accessed urgent care was seen. The Royal College of Emergency Medicine, after noting the significant reduction in patient attendance and a rapid reconfiguration of emergency departments in response to the pandemic, stated that emergency departments “must not become crowded ever again” (RCEM, 2020, p.1). New measures to access urgent care were introduced, and all patients were encouraged via a media campaign to use NHS111 prior to attending the emergency department. NHS111 could then stream patients to a health service considered to be the most appropriate to meet their health needs. This might be to the walk-in centre, a GP, or an alternative out of hours provider, thus diverting attendance from the emergency department whenever possible (NHS England, 2021).

Within months, however, both adult and paediatric attendance at emergency departments increased significantly yet again until it exceeded pre-pandemic levels. A number of reasons were thought to account for the rapid return in patient numbers. These included a growing demand for urgent intervention for people with longer-term conditions that they might have been trying to self-manage at home. Furthermore, the media had already reported on the reduction in attendance at emergency departments and sent out the message not to delay seeking medical help, so there was no longer a message of deterrent given to people experiencing mild acute illness (Reschen et al. 2021). In addition, the RCEM cited an increase in the GP workload and subsequent lack of access to GP appointments, patient’s unhappiness with virtual consultations, and their concerns over a missed diagnosis as factors in steering patients to emergency departments instead. It found that calls to NHS111 had also increased along with the number of low acuity patients being advised to attend an emergency department by the service. These were patients who, according to RCEM, did not need to attend (Sarsfield & Boyle, 2021).

There was recognition of the disproportionate number of children attending the emergency department, and it was noted in this study that younger children had become frequent attenders as they began mixing socially or attending nursery, with parents baffled by the number of illness their child seemed to be experiencing. This was soon acknowledged as a national problem by the RCPCH which reported increasing pressures on emergency departments from the rise in children with mild illness brought by anxious parents, unused to their child being unwell. The RCPCH claimed that parents were taking their child straight to the emergency department, rather than seeking help at pharmacies, their GP, NHS111, or online (RCPCH, 2021).

However, the RCPCH's assertion was not supported by the findings of this study. From nineteen interviews completed over the pandemic period, only 2 parents made an independent decision to attend the emergency department. Three parents sought advice from family or friends, and fourteen parents were advised to bring their child to the department by NHS111 or their GP surgery via telephone. It was evident that parents had responded to the campaign to contact NHS111, but many waited several hours to receive a return call only to be advised to seek a GP review or attend the emergency department. Parents then believed that they had to follow the advice, even if they did not feel that attendance at the emergency department was necessary.

> *"I contacted NHS111 who said they would get the GP to call me. I felt like I had to wait to speak to the GP rather than just come straight here. Then the GP told me to come here anyway."* **Mother – Interview 27**
>
> *"It was my mum who said, 'just ring NHS111 for some advice'. They said see our GP, but they couldn't fit us in so told me to bring him here. I didn't really feel like we needed to come to A&E with this but felt I didn't really have a choice. I probably would have just kept him at home."* **Mother – Interview 28**
>
> *"I rang NHS111 last night at 11 o'clock. Her temperature was 40. By the time they rang me back at 5 this morning, we were all asleep. I didn't even hear the*

> *phone ring, but they left a message telling me to see the GP if I was still worried. I rang the GP. They said come here. I wouldn't have come unless I had to, but the GP said I had to come."* **Mother – Interview 32**
>
> *"I will not use NHS111 again, waiting on the phone seeing my child groaning and poorly. This puts my baby at risk waiting this long. I wouldn't do that again."* **Mother – Interview 34**

In summary, there has been a unique opportunity to observe if the national response to the COVID-19 pandemic and the governments slogan "Protect the NHS" made a difference to how parents managed their unwell child and accessed healthcare. Indeed, there was an early assumption that the initial drop in attendance was because parental help-seeking behaviour had changed as the threshold to seek medical assistance became higher. It was thought that parents preferred to manage the illness themselves rather than risk exposure to COVID-19 infection in the hospital (Isba et al., 2020). However, it became evident that children had suffered fewer infections while social distancing measure were in place. Once children returned to mixing with others at nursery or school, the demand for healthcare soared as they contracted common childhood illnesses again.

This study found that the level of parental anxiety for their child had not been altered by the pandemic. Parents continued to be concerned and sought medical help early in their child's illness. They preferred to access services appropriately but expressed frustration at the increasing difficulty they experienced when trying to obtain a GP appointment or to use the NHS111 service. Several parents expressed their concern over telephone consultations which they did not feel were always adequate to assess their child accurately. Other parents just wanted advice or reassurance and were frustrated at the lengths to which they had to go to achieve this.

CHAPTER 5

DISCUSSION

The intention of this study was to explore the psychosocial influences on parents' decisions to bring their child to the emergency department with a mild to moderate illness. The current model of health care is structured around a hierarchy of need and the emergency department is intended to meet the most urgent need for healthcare. Yet 60% of paediatric attendances are deemed non-urgent and suitable for management in a primary care setting (Watson & Blair, 2018). Earlier studies have focused on the reasons for parents attending the emergency department unnecessarily and are generally inclined to blame parents for their help seeking behaviour and perceived inappropriate use of the emergency department.

The findings from this study challenge some of the assumptions or conclusions that imply criticism of the parent for overuse of the health service. Instead, it highlights the accountability for the rising demand for health provision for children with a mild acute illness as shared between the HCP and the health system. Parents explained their concerns, balancing their actions with doing what they judged to be the right thing to do, and seeking the right service to obtain the best and most appropriate care. In doing so, parents often experienced a complex journey as they navigated a healthcare system that, in an effort to offer a simple tiered system, instead became fraught with obstacles along the way.

Throughout the study, parents frequently referred to their interactions with a HCP, and it became apparent that such interactions were significant in affecting their experience, their confidence as a parent, and their help seeking actions. Accordingly, this became the pre-eminent finding that emerged from the data analysis, affording novel insight into the influence of the HCP working within the health care system and the ensuing repercussions of how parents access healthcare. While it was not intended for the design of this study to be directed by any theoretical framework, the findings led to a search for an applied method to understood and interpret the relationship between the parent and the HCP at a conceptual level. The application of social theory was selected to make sense of human behaviour and the influence of power and social structure on how behaviour is reproduced or transformed.

5.1 SOCIAL THEORY AND GIDDENS THEORY OF STRUCTURATION

Some approaches to social theory emphasise the power of structure as constraining human action, proposing that human behaviour is controlled by the environment in which people function. Alternatively, it is argued that it is human choice and behaviours that exert the power to produce and reinforce structure. Rather than seeing behaviour as a product of society, society (or structure) is determined by human behaviour (agency).

Work by Giddens (1984) sought to overcome the division between the polarised nature of structure and agency, recognising that both concepts are intimately related and that neither approach can exist independently. He proposed a theory of structuration that combines structure and agency, exploring the process that occurs at the interface between the agent and the structure. He suggests that agency takes place within the framework of rules devised by social structure, but it is only because the agent conforms to these rules that they are reinforced. This means that the structure is reliant on the compliance of human action to maintain stability. Giddens then believes that agents will then use reflexivity to examine and revise their actions in response to new knowledge and experience and can choose to act outside the constraints or rules of the structure. As a result, structures are modified by a change in human action and agency. (Gibbs, n.d.; Giddens,1984; Haralambos & Holborn, 2013). According to Giddens, this reciprocal relationship between structure and agent represents a duality since the structure and agent are not two independent phenomena but overlap in their ability to constrain and enable one another (Giddens 1984; Whittington, 2015).

Structuration theory does not easily lend itself to full empirical application, however, Giddens sees structuration theory as a method of sensitising and pointing the researcher towards phenomena rather than a precise theory. Accordingly, the researcher does not need to apply the framework in its entirety but is able to draw on parts of structuration theory to identify meaningful concepts successfully (Hardcastle, et al., 2005; Whittington, 2015). Pertinent to myself as the researcher and working as a HCP within the structure, Giddens recognises that mutual knowledge may remain latent when the researcher and the research occupy a common social environment. Intentionally applying conscious investigation using the language of social science will illuminate what is already known, what is unintended and what is unacknowledged, thereby revealing what is hidden (Giddens, 1984).

In the context of this study, it was observed that parents, as the agent, responded to their instinctive concern for the welfare of their child but also conformed to the rules imposed by society as they endeavoured to do the right thing. They adapted and developed their help seeking behaviour (agency) in response to their interface with the health structure and the HCP working within that structure. The HCP was also recognised as an agent working within the safety of the health structure, but with the power to convey to parents that they were complying or breaking the rules of help seeking. The HCP held the power to enable the parent to access the resources of the health structure. Following a period of reflexivity, some parents were able to develop confidence in approaching health services, while other parents responded with vulnerability at the risk of criticism. The agency of the HCP and the health structure were seen to influence a parent’s ongoing agency with health services. In many instances, parents were advised to attend the emergency department, or there had already been multiple contacts with different services. The current structure of the health service arguably perpetuates the pressures that are currently experienced, including the persistent rise in attendance at the emergency department. Giddens concept of duality offers the potential for change since the agency of health seeking will change the structure of the health system, and in turn, the structure of the health system will change the agency of health seeking.

In order to make sense of the data and the interrelation between social factors and parental thought and action, Giddens theory of structuration was considered an apposite framework to organise the conceptual discussion.

	DEFINITION	APPLICATION	
STRUCTURE	A set of rules that create and sustain a system. The rules are maintained by the agents compliance. Modification to the rules occurs with non-compliance and a subsequent change in human behaviour or agency.	The structure of rules that govern behaviour are the separate systems of **parenthood** and the **NHS.**	↑ **THE DUALITY OF STRUCTURE** **The behaviour of the agent is determined by the rules of the structure. In turn, the rules of the structure are reformed by the reflexively modified behaviour of the agent as they respond to new information.** ↓
AGENT	The individual or person who has the power to constrain or enable through agency.	The individual agents with power are recognised as both **parent** and the **HCP.**	
AGENCY	The capacity to act based on human choice and behaviour, directed by following rules and social norms. Using reflexivity, new knowledge and experience are able to change behaviour and subsequently the rules.	Both the agency of parents and the HCP are powerful in changing behaviour. The HCP is most powerful as the holder of knowledge and resources. Parents regained power if they were given cause to doubt the authority of the HCP. They began to work outside the rules of the structure to get the help they wanted.	

Figure 3. Application of Giddens Theory of Structuration in this Study

(Giddens,1984)

5.2 THE AGENCY OF PARENTHOOD

The study found two fundamental motivators that direct parents help seeking behaviour. These are the natural and instinctive desire to protect their child from harm and the powerful influence of social structure. The role of the parent is conventionally accepted as loving and nurturing their child safely towards independence and adulthood (Abraham et al., 2014; Gross, 2020). The concept of attachment between the child and parent is central to any discussion on parenting and seminal work by psychologist Mary Ainsworth recognised that a crucial feature influencing attachment is sensitivity (Gross, 2020). The sensitive parent or carer is able to interpret their child’s signals and respond by providing for the physical and emotional needs of their child, protecting and keeping their child safe.

The parent develops expert knowledge of their child and should the child become unwell, parents demonstrate their ability to recognise and respond to the signals from their child that represent signs and symptoms of illness. The parent’s sensitivity to the health needs of their child defies inaction as they balance the risk that the illness is harmless with the risk of their child developing a serious illness. The media report stories of child loss and parents may be aware that, since it has happened to others, it could happen to them.

Confirming that a parent’s concerns for their child do not change fundamentally, the findings of this study reflect those of the historic study by Kai (1996). Parents responded to the same triggers of mild illness with an overwhelming sense of responsibility to ensure the safety of their child, unable to ignore their anxiety and fear that the child might come to harm. It is therefore inevitable that parents will respond sensitively, consistently and appropriately by seeking help for the continued care of their child.

Once they have responded to their instinct to safeguard their child, the parent may then turn to consider their actions within the wider demands of social structure. According to Giddens (1984), the macro of social structure is constructed by the micro of social practice. Initially, the parent will participate in social practice by undertaking regular and ordinary activities of day to day living and caring for their child. Actions may remain instinctive, but they are strongly influenced by the current customs and conduct of how to be a ‘good parent’.

Regular social practice then brings people together into various levels of social systems such as family, work, and healthcare, with each system bringing its own pressures and expectations (Whittaker, 2015). It was evident that parents in this study found themselves negotiating between the two divergent social structures of parenthood and the health service, striving to act appropriately based on what they knew of the rules for each structure. This was exemplified by one mother who explained her angst at feeling helpless at seeing her daughter in pain, but did want to be seen as wasting the resources of the NHS or peoples time.

5.2.1 The Rules

Giddens (1984) claims that it is social interaction that determines the rules and norms of social practice which subsequently provide the conditions for agency within the social structure. This would suggest that primarily, a conversation or social observation takes place to confirm the rules which then proceed to validate a course of action. For the parents in this study, it was important to be seen to act correctly and responsibly since almost every parent had sought some form of advice prior to attending the emergency department. According to Giddens, knowing what to do provides agents with a sense of safety, a coping mechanism (Hardcastle, et al. 2005). In seeking another opinion, parents had gained support for their actions as they conformed successfully to the structure of parenthood and sought help for their child responsibly. This allowed the parent to feel further reassured that they were conforming to the rules of the health structure too. However, this was not guaranteed.

Criticism was conveyed by the HCP when it was perceived that parents had broken the rules of the health structure by accessing healthcare unnecessarily. Despite the parent initiating the encounter, the HCP was able to control the interaction and invoke rules from their position of authority within the structure of health (Hardcastle et al., 2005). However, Giddens claims that rules within a structure are not implicitly formulated but only verbalised. This means that rules can fluctuate around an individual’s adaptation or interpretation. In the health structure, interpretation of rules may change according to the pressures of being busy or understaffed, or mixing the demands of particularly unwell patients with those with less severe health needs. Subsequently, criticism was conveyed to parents on the basis of tacit rules that were not known to them as they moved into a structure remote from their usual experience.

5.2.2 Acting Outside the Rules

Giddens believes that social structures are only reinforced by the compliance of the agents acting within the rules. Yet by the exercise of reflexivity, agents respond to new information and are able to revise their social practice, acting outside of the rules that the social structure has imposed discursively. Giddens speaks of reflexivity as being “grounded in the continuous monitoring of action which human beings display and expects others to display” (Giddens, 1984, pg. 3). In particular, he refers to interaction within the context of diverse circumstances and settings as the rationalisation for action and the basis upon which the competence of agents is evaluated by others (Gibbs, n.d.; Giddens, 1984; Hardcastle et al. 2005).

This is characteristic of the interaction between parents and HCP within the diversity of the health care setting. There is an imbalance in the effect that the interaction may have on either participant. Worry and unfamiliar circumstances mean that by the nature of their position, the parent is vulnerable and sensitive to criticism.

The study found that parents could vividly recall the interactions from which they felt dismissed, that their concerns were not valid, or that they were timewasters. It might only have been a fleeting comment from the HCP, or an attitude that was perceived as being condescending. Parents sensed that HCPs did not listen to them, and several parents referred to feeling ‘fobbed off’. It is possible that the HCP felt that they were being reassuring by saying that there was nothing to worry about, but time constraints limited the opportunity for further explanations, information giving and advice on how to manage the illness. One mother described how she left a consultation, feeling dismissed and still worried, uncertain of what she should do next (interview 18). This was not atypical. As a consequence, parents felt that that they should not have worried in the first place and this led to self-doubt and confusion and a distrust in their ability to judge their own actions.

Parents modified their behaviour to avoid being discredited. The study by Neill et al. (2013) found that the desire to avoid criticism can result in a delay in seeking a medical consultation. Similarly, one mother in this study referred to her sense of guilt when she had previously kept her sick child at home for too long because she did not want to trouble HCPs unnecessarily. Initially torn between the plural rules of the health structure and parenthood, the mother reflexively revised her actions in response to new information that the health of her child had been jeopardised by her attempt to adhere to the rules of the health structure. She no longer experienced any concern about seeking help much sooner and was less worried about her personal interaction with a HCP, instead responding to her instinctive desire to care for and protect her child.

For parents of unwell children, the process of reflexivity instigated an evaluation of the competence and rules of the health structure based on experiences and produced a sensitised response. Parents referred to previous encounters with the health service and how they monitored and revised their actions and began to work outside the discursive rules of the structure. Based on such experiences, they justified their decision to attend the emergency department.

The study found that the majority of parents had responded to the government message to use alternative health care provision instead of attending the busy emergency department. Parents had anticipated, since they had complied with this message, that the services would be simpler to access. Instead, parents expressed their frustration as they attempted to access the health structure appropriately, perhaps by contacting the GP surgery or NHS111, but were thwarted by long waits and poor communication.

They found encounters with the various systems within the structure problematic and difficult to navigate and this eroded their confidence in the structure. A significant number of participants in the study were advised to attend the department by a HCP, often without being examined, or after contacting NHS111 for advice. The implications of these instructions were raised by several parents in the study who referred to their encounters with alternative health providers as “pointless” or as the “middle-man”, and so on this occasion they had chosen to attend directly to save time.

For some parents, the experience at the emergency department compared favourably to a contact with primary care. The parents did not have to battle through long waits on the telephone or waiting for an appointment to have their child examined. Similar to the findings of other studies (Rowe et al. 2015; Holden et al. 2017), parents referred to the environment and the perception of available expertise as being preferable to attending the GP surgery. Ultimately, however, this study found that regardless of where the child was assessed, it was the parent's perception of being heard and having their concerns addressed that made the most difference.

5.3 THE AGENCY OF THE HEALTH CARE PROFESSIONAL

It has been established that integral to the parent's experience of health care is their interaction with the HCP. Since parents depend on the HCP to provide access to the care and services that they need, there is a natural imbalance of power within the interaction that sees parents as the help seeker and the HCP as the help giver.

5.3.1 Power

According to Giddens (1984), power increases a person's capacity for agency. Agency refers to the capability to act so the more knowledge an agent has about their social context and structure, the more power they have available to influence the circumstances and the actions of others. In an institution as old as the NHS, the continuity of power is maintained through the accepted relationship between the agents, the HCP and the parent, assuming an unspoken agreement of who has control and who is dependent in the framework of social interaction (Giddens, 1984; Hardcastle et al. 2005).

Furthermore, Giddens (1984) sees the media through which power is exercised as having the ability to control resources. He breaks down resources into two types: authoritative, the command over people; and allocative, the command over object or materials. In the context of health care, the HCP is able to exert both authoritative and allocative control using their knowledge and their position in the health structure. This enables the HCP to act as the gateway standing between patients and further services and treatment. For that reason, the characteristic forms of interaction that might occur between the HCP and the parent will commonly be dominated by the HCPs authority and expert knowledge of the rules and boundaries of the health structure. Through interaction, the HCP conveys these rules and parents must attempt to regulate their behaviour accordingly.

According to the Giddens concept of *duality of structure*, rules of the structure are susceptible to reproduction, renegotiation or redefinition following a period of reflexivity. For the HCP as an agent working within the structure of health, rules that might see their social position as primarily one of compassion and care may be reshaped when the HCP experiences increasing pressure to meet the rise in demand for services within the boundaries of targets. The priority changes as the HCP responds to the expectations of the targets rather than the expectations of the patient. It is doubtful that the intention of the HCP is for their interaction to be detrimental or dismissive of the parent's concerns, but the demands on time and pressures of the service can result in unintentional blame apportioned to the help seeker. As a consequence, there is an expectation from the HCP that the behaviour of parents should comply with newly modified rules of the health structure, since criticism is conveyed when the parent does not do so.

Worried parents are not usually health professionals (Vestal, 2019), and parents do not wish to experience conflict when they are already anxious about their child and entering another structure where the rules are unfamiliar. Giddens (1984) points out that conflict will occur if there is a struggle between the actors of different social practices and if there is a division of interest between different groups of people within a social structure. Either group may experience conflict and as a result, contradictions arise in the structures purpose. Parents might assume that the purpose of the health service was to offer any level of assistance to care for their child, in contrast to the HCPs perception that the parent was still able to care for their child without their help. The HCP assumes that the parent should have knowledge, but the parent is seeking help because they do not have the required knowledge. It is probable that the HCP will conclude the health consultation without ever realising the impact of their interaction on the parent. Since it is unlikely that the HCP will experience any repercussions from the interaction, it is doubtful that they will apply reflexive monitoring. Their behaviour remains uncontested, reproduced and institutionalised and will further reinforce the inclination of the HCP to blame parents for their helps seeking actions. Inevitably, parents continue to risk conflict and criticism, always remaining one step behind in their knowledge of the changing rules.

5.3.2 A shift in power

So far, the discussion has considered the position of the HCP as being more powerful than the position of the parent, yet parents in the study illustrated how they were able to overcome the variance in power to secure the help that they wanted for their child.

Giddens reasons that if an agent has any capacity for agency, they retain power within the social structures. He calls this the *dialectic of control* which recognises the "two-way character of the distributive aspect of power; how the less powerful are able to manage resources in a way to exert more control over the powerful in established relationships" (Giddens, 1984, pg. 374).

A number of scenarios were identified by the study that saw a shift in power away from the HCP towards the parent. Parents continued to access services if they felt that the HCP had given a misdiagnosis or had not offered a sufficient explanation of their child's illness. Parents assumed that the HCP was not confident or did not have the knowledge to diagnose the illness.

Several parents questioned the guidance given by the HCP after they had chosen to access lower tier services for advice yet were offered an ambulance or told to take their child to the emergency department, or, having chosen to attend the walk-in centre, were diverted to the emergency department. Parents with low levels of concern felt that they must have underestimated the severity of their child's illness whereas other parents declared that they did not feel that their attendance at the emergency department was necessary. Having been told to take their child by a HCP, they felt that they had little choice as this was the safest option and they feared repercussions if they did not attend. Yet the minimal medical intervention that their children required confirmed their initial belief that they had not needed to attend the emergency department.

The disparity in advice and management from the HCP eroded confidence in the health structure and gave parent's permission to challenge the knowledge and the power of the HCP. As a result, parents were less likely to conform to the rules of the health structure, or they modified the rules based on their experience; if a GP could treat the emergency department as the default place to attend, then so could the parent.

5.4 THE STRUCTURE OF THE HEALTH SERVICE

Giddens theory of structuration emphasises that agents and structures are not two separate entities, but represent a duality, since neither structure nor agency can exist independently but form a reciprocal relationship. Accordingly, social structures are embodied in the choices that agents make and at the same time, agents are able to form and reform social structures by their actions (Giddens, 1984, Hardcastle et al. 2005). It was evident throughout the study that the drive in the demand for paediatric urgent care services was perpetuated by the complex systems established within the NHS structure and the interrelationship between parents and HCPs.

5.4.1 The NHS as an Institution

Giddens proposes that when similar social practices become established over a wide span of time and space, the framework of rules become chronically reproduced, the structural properties become deeply embedded and an institution is constructed (Giddens, 1984). Typical of a structure the size of the NHS, Giddens sees institutions as the most enduring features of social life that provide solidity and continuity which, through consensus of action, gives the institution power and authority (Hardcastle et al, 2005; Whittington, 2015). The power of the NHS is well defined since people are reliant upon the health knowledge and resources that it provides.

Since its inception in 1948, the NHS has brought significant improvements to health and wellbeing. Accompanying its success however, there has been a gradual rise in public expectations and an increasing dependence on the health service to encompass every health need (Rivett, 2019). Media campaigns to raise awareness of serious illness, have also served to escalate worry and a sense of urgency to seek health care, even when symptoms are mild. There is a growing intolerance to wait to see if illness will self-resolve when it interferes with getting on with modern activities of every-day life (O’Cathain et al. 2019).

In response, the NHS has evolved into an expensive, complex and vast system that does not easily lend itself to reconfiguration and change is often slow. It has proven difficult to radically transform a service that is continually in use and instead additional services have been bolted on to what already exists.

Within the speciality of urgent care, alternative services have been put into place that intend to deflect minor illness away from the emergency department and make it easier for patients with less acute illness to access treatment and advice rapidly. Since attendance to the emergency department continues to rise, and alternative health providers are also reporting overwhelming demand (RCEM, 2021b), these do not appear to be achieving their original intention to ease the pressures on urgent care services. Indeed, Giddens (1984) points out that actions intended to reform a social structure may have unintentional consequences which perhaps in this instance have seen increasing use and multiple contacts between the various available health services, contacts that are initiated by both the patient and the HCP (Nicolson et al. 2020).

5.4.2 The Agency and the Actors

Even powerful institutions would not exist without the capacity for human agency since it is only the actions of the agent that see their reproduction or their transformation (Giddens 1984). Within the setting of the NHS, both the HCP and the patient are agents, operating from different social positions but situated within the same structure. According to Giddens (1984), agents will draw upon their knowledge of the structural context and are then able to combine rules and resources in different ways and with different intentions. This enables greater agency for some, while constraining the agency of others. The actions of parents were constrained by the authority and knowledge of the HCP, but equally, the HCP experienced constraints imposed by pressures on the service and a conceivable rise in expectations from the parent.

5.4.3 Agency within the Institution of the NHS

The discussion has so far recognised that the agency of parents is to responsibly and sensitively seek help when their child is unwell. When they needed to access the resources of the NHS, the majority of parents in the study responded to the rules of the health structure and attempted to seek health care appropriately by contacting the GP or NHS111. However, parents were often constrained by a difficult and frustrating journey as they navigated their way through the complexities of the institution before their arrival at the emergency department.

Within the structure of the health service, it is anticipated that the agency of the medical profession is to offer a good standard of practice and care within the extent of their knowledge and competence (General Medical Council, 2013). Yet more than half of the parents in the study were directed to the emergency department by other services within the system, whose purpose was to reduce rather than increase attendance. This may have been after a conversation with the GP surgery who had advised that there were no appointments available, or parents had been told that the child should attend the emergency department even when the parent had described symptoms of a mild illness. Several parents questioned if their attendance to the emergency department was necessary.

It is beyond the scope of the findings from this study to debate the reasons why HCPs advised parents to take their child to the emergency department, but a previous study by Conlon et al. (2021) found that the HCP may be constrained by professional inexperience, or a ‘better to be safe than sorry’ approach, or a perceived pressure from parents to send their child to the hospital as contributing factors. Several parents from this study reported that the HCP could not offer an explanation of the illness or a diagnosis. Instead, the HCP referred the child to the emergency department. It is understandable for any HCP that they do not want the responsibility of failing to recognise a serious illness in a child, but apprehension will drive a minimum risk approach and defensive practice (Bradford-Duarte et al., 2019). The constraints of defensive practice are evident in the emergency department also, as studies by Rowe et al. (2015) and Holden et al. (2017) observed children experiencing prolonged periods of observation or investigations that served to reassure both parent and the HCP and justify management decisions, even for mild acute illness.

In this way, the constraints on the agency of the HCP caused by professional anxiety and cautious management enabled the parent to validate their attendance to the emergency department and will arguably perpetuate their attendance in the future.

5.5 THE THEORY OF STRUCTURATION AND THE RISE IN PAEDIATRIC ATTENDANCE TO THE EMERGENCY DEPARTMENT

Using Giddens theory of structuration, the discussion has focussed upon the interrelation between the parents and their help seeking actions, the social position of the HCP and the structure of the NHS as a stable institution. The theory has explicated the behaviours that are influenced by the rules of a structure, and that these rules may be reinforced by compliance or changed following a period of reflexivity. Parents acted sensitively to the needs of their child and in response to the more familiar rules within the structure of parenthood. Parents felt vulnerable when they ventured into the less familiar rules of the structure of health, when already experiencing high levels of anxiety driven by concern for their child. They often sought informal advice prior to formal advice to address their uncertainty and validate their decision to access the health services.

Giddens reiterates that everyone has power, but some more than others depending on their knowledge and access to rules and resources (Giddens, 1984; Hardcastle et al. 2005). Utilising Giddens structuration framework expanded the investigation into the power that the HCP holds over the access to healthcare because of their knowledge and control over resources. It was observed how increasing demands on their time, and pressures to achieve NHS targets created conflict and criticism that was conveyed in their interaction with parents. As a result, parents told of how they often felt rushed or dismissed. A lack of advice or information meant that they had gained little from the consultation and continued to feel uncertain about the care for their sick child.

Importantly, the study found that parents would reflexively modify their behaviour should the actions of the HCP not alleviate their concerns for their child or convey expertise. Parents regained power and worked outside the rules by questioning the knowledge and authority of the HCP and continuing to seek help.

In response to the rising demands for urgent care, the NHS has provided alternative services with the intention of deflecting patients away from the emergency department. An unintended consequence of this has become inter-agency referrals between the services as a second opinion is sought, or because of time constraints and a lack of available appointments in primary care, or defensive practice by the HCP. Patients have the option to self-present to more than one service should they perceive that their concerns were dismissed, or the HCP did not provide the care that they sought.

Accordingly, the findings from this study have been able to demonstrate how the combined agency of the parent and HCP, working within the embedded rules of the NHS institution each share the responsibility for the drive in the attendance to the emergency department. There is irony that advances in healthcare have ensured that serious illness in children has become uncommon, but the health system is finding it difficult to meet the needs of children who suffer from a mild acute illness.

The study has identified a clear need to improve the service provision for children with mild acute illness since the current system does not alleviate but perpetuates help seeking behaviour. While Giddens concedes that the institutional rules of an organisation such as the NHS are more resistant to change, he insists that, while there is potential for agency, the capacity for transformation remains (Giddens, 1984).

5.6 THE FUTURE OF URGENT CARE FOR CHILDREN

Without doubt, the NHS has worked to improve paediatric services within the emergency department and standards devised by the RCPH (2018a) have seen departments providing a child friendly environment with dedicated paediatric facilities and healthcare. Yet similar guidance appears lacking for the alternative services that provide urgent care for children. The NHS Long Term Plan (2019) recognises that children account for 25% of attendance to the emergency department and are the most likely age group to attend the emergency department unnecessarily but makes no suggestion as to why this might be the case or explore more appropriate alternative provision for children. The Urgent Treatment Centre model outlined in the NHS Long Term Plan forms a blanket term for NHS111, primary care, community pharmacists, ambulance and other community-based services, describing these as a convenient alternative to the emergency department. Yet the parents in this study who tried to adhere to the advice to use alternative services encountered frustrating journeys through the system. They received mixed messages and criticism, and experienced unnecessary and counterproductive visits to the emergency department.

The services that are currently in place have been designed around the concept of the HCP and their professional understanding of what patients need. There is minimal reference to specific provision for children within the plans for future improvements to urgent care services. In particular, there appears to be little acknowledgement or consultation with the child and family to ascertain the type of service that they want, which seem at variance with the HCPs perception of what they need.

The absence of reference to the specific needs of children reinforce the findings from the independent report on services for children and young people by Sir Ian Kennedy in 2010. He pointed out that health services are designed around the needs of adult care with little concession made for the needs of children. He expressed the same concerns that parents are expected to navigate a complex range of services when their child is unwell and that it becomes understandable why the simplest route is to the emergency department (Kennedy, 2010). Despite the length of time since the publication of Kennedy's report, there remains considerable discrepancies between service provision and service demand. As a result, both the HCP and the parent experience frustration with a health system that fails to fulfil the expectations of either individual. group

5.6.1 What Health Service Do Parents Want When Their Child is Unwell?

The application of Giddens theory of structuration has demonstrated the capacity for change, even for an institution whose rules and structure are as large and embedded as the NHS. Giddens refers to the concept of motives that influence actions in more unusual circumstances and this was apparent when parents acted outside the perceived rules when they were worried about their sick child. Interestingly, Giddens sees that motivation is the potential for action based on the wants that prompt it (1984). It is worth considering the study findings from the parent's spoken experiences to establish the kind of health service that they want available when their child is unwell if the future design of services is to be efficient and effective.

Instant Access

The study found that it was important to parents for them to gain rapid access to a health assessment. Responding to media campaigns that raised awareness of serious illness, parents did not want to take the risk that their child may deteriorate while they waited for an appointment or return phone call.

Telephone Advice

Parents valued the potential ease of making a phone call to NHS111 for advice, but did not want to experience long waits on the telephone, or the promise of GP appointments that turned out to be unavailable. They did not want to be told to attend the emergency department if they felt that this could be avoided.

Paediatric Environment

Parents valued a dedicated paediatric environment which conveyed paediatric expertise and recognised the unique needs of a child and family. Parents recognised that the quality of care was compromised when the department was busy and overcrowded.

Paediatric Expertise

Parents wanted to be able to trust the HCP and feel confident in their expertise. This was conveyed when their child was examined thoroughly to make sure that all potential causes of illness had been considered and information and advice was offered by the HCP. They wanted consistency and communication between the various services that led to continuity in care.

The Time to Listen

Ultimately, parents wanted time to be seen and heard, regardless of where their health encounter took place. Parents wanted to feel that both they and their child were cared for. They described their sense of relief when they felt listened to, when their concerns were treated respectfully by the HCP and when they were acknowledged as the expert on their child seeking advice from an expert in healthcare. For parents, this was their precious and beloved child and they wanted the HCP to recognise their individuality rather than being referred to as a symptom. One mother had spoken of a previous difficult encounter and following her experience, was poignant in her description of what she wanted from the health service as a parent of a sick child.

> *"I don't want to be dismissed. I don't want to have to fight. It's often the small things like caring for me too. It's the kindness shown."* (Mother - interview 35)

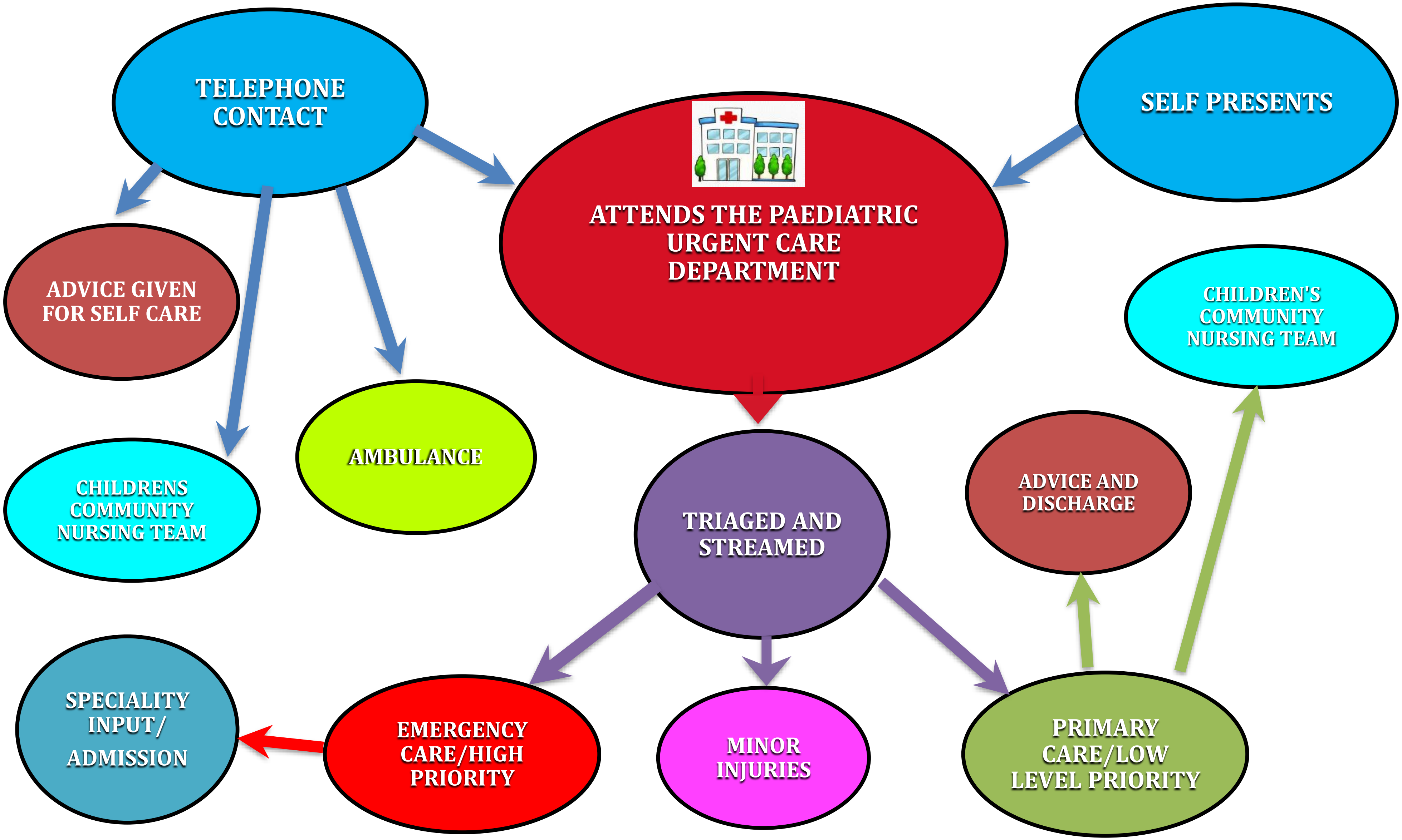
5.6.2 The Model for Change

The NHS Long Term Plan (NHS 2019) passes the responsibility to individual health trusts to design and implement appropriate models of care for children's services in response to the needs of the local population. I am fortunate to be in a unique position where the current urgent care services are being remodelled with the building of new facilities over the next two years. From the findings of this study, I intend to propose a new model of paediatric urgent care that will see services co-located in a paediatric central location situated within the extended paediatric emergency department. The intention of the model is to rebrand urgent care to provide one point of access that can offer minimum to maximum levels of care and intervention in a timely manner. The model is able to offer a telephone advice service giving guidance on self-management, arrange for a children's community nurse to visit the child at home, advise the parent to bring their child to the paediatric urgent care centre or arrange for an ambulance if necessary. Should the family present directly to the centre, the child will be assessed and streamed to an appropriate care provider within the department. These will include separate areas for children with a mild to moderate acute illness, minor injuries and for children who are more unwell and need emergency care. Advantages of this model will be the removal of confusion for parents when their child is unwell along with the pressure to 'do the right thing'. Paediatric expertise is co-located in one place within a specifically designed paediatric environment that recognises that children are part of a family and the needs of parents are as important as those of the child. As paediatric staff work together, consistency in care and communication between the services is ensured.

There will be a significant opportunity for the paediatric HCP to improve the health literacy of parents by offering current information and expert advice from recognised credible sources. This will aim to keep parents up to date with changes and advances in the management of childhood illness with the intention of increasing parental confidence when caring for their unwell child. The paediatric urgent care centre remains a safety net if parents continue to need further reassurance.
Since families will be attending a purposefully designed service that intends to stream children to the most appropriate area to meet their need, it is anticipated that parents who need support caring for their sick child will feel welcomed by the HCP rather than dismissed. It is hoped that parents will feel confident to approach services who will offer support and guidance to empower and enable them to continue to care for their child.

It is currently beyond the scope of this study to consider the financial and practical aspects of this model in their entirety but it is anticipated that this will be a cost effective and efficient service design. Variations of many of the features of the model are already operating but in different locations. For example, within the Trust, there is a Digital Health Team who take the NHS111 calls for the area and are able to stream patients for to the most appropriate service to meet their health needs. The model would see advanced streaming for children and greater communication between the two services.

Figure 4. Proposed Model for Paediatric Urgent Care



5.7 LIMITATIONS OF THE STUDY

The findings of this study were limited to the research participants being recruited from one district general emergency department. However, it was felt that participants were a typical representation of the wider intentions of parents who seek help for an unwell child. As a researcher in the workplace, there was concern that parents may feel inhibited in sharing any criticism, but this was not found to be the case. Parents welcomed an opportunity to talk about their experiences and how this made them feel.

The sample size was reduced from 50 to 35 following the onset of the COVID pandemic which saw a decline in paediatric attendance to the emergency department and available participants due to the reduction in attendance to the emergency department. This was not unique to this hospital but was an international phenomenon during the first months of the pandemic (Goldman et al. 2020; Scaramuzza et al., 2020). As the interviews continued, it was noted that there were many commonalities in the experience of parents and the reduction in participants is not considered detrimental to the study findings.

The intention of the study was to explore the expectations of the parents visit to the emergency department and compare these with their actual experience in a follow up telephone call two days later. Firstly, it was soon realised that parents could describe few expectations other than they may have to wait a long time, and that they would be seen and assessed by a HCP. Secondly, the opportunity to continue the follow up telephone call was prevented by the pandemic, since the telephone call needed to be made from the hospital to protect confidentiality and the hospital was restricted to essential access only. However, parents were willing to speak about their current experiences and their previous encounters with the health service and how this made them feel. This provided quality data from which to conclude the type of health service that parents want to access when their child is unwell.

CHAPTER 6
CONCLUSIONS

6.1 REVIEW OF THE RESEARCH QUESTION AND OBJECTIVES

The following research question was devised to establish the behaviour and the social processes involved in the parent's decision to attend the emergency department and to explore their journey through the healthcare system.

What are the concerns, expectations and experiences of parents who choose to bring their child to the emergency department with mild or moderate acute illness?

This study set out to explore the psychosocial influences on parents' decisions to bring their child to the emergency department with a mild to moderate acute illness. The significance of these for the sustained rise in the numbers of children visiting the department has been considered. Overwhelming demand on urgent care services has led to many presentations being deemed 'inappropriate', and criticism is often conveyed to the parent for their help-seeking behaviour. A gap in the research was identified that captured the immediate drivers behind the decision to attend by conducting a contemporaneous interview while parents were in the emergency department. Whether or not the judgement of 'inappropriate attendance' was deserved was investigated by exploring parent's thoughts, behaviour and experiences prior to their visit. The provision for urgent healthcare preferred by parents when their child is unwell was elicited.

The Objectives of the Study

1) To assemble a varied sample of parents of children presenting with a variety of non-urgent medical illnesses (triage score 3 or 4, or 2 and discharged home)

A varied sample of 35 participants was achieved. The onset of the COVID-19 pandemic saw a drop in attendance at the emergency department and meant the collection of data became a longer process than originally intended. This allowed for wider speculation that parents were preferring to manage their child's illness independently. However, once the lockdown restrictions were lifted attendance rose again, and parents' concerns and help-seeking actions were shown not to have changed.

2) To identify predisposing factors behind the decision to attend the emergency department. These might include the concern for their child, previous help and advice sought, previous experience of services or having an unwell child.

The predisposing factors were successfully identified. These were parental concern, a sense of responsibility, and the management of risk to their child. The majority of parents sought advice from family, friends or the health service, and more than half of parents were advised to attend the emergency department by another HCP.

3) To explore parental thoughts and feelings about caring for an unwell child and accessing support from health professionals and services.

It was found that parents wanted to do the right thing for their child without increasing the burden on the health service. They navigated their feelings of conflict and the risk of receiving criticism at their decision to attend the emergency department, but these were superseded by their concern for their child.

4) To elicit the expectations held by parents of the health service that would be offered, their perceived response from the health care professional caring for their child, and the outcome of the visit.

It was anticipated that exploring parental expectations would be insightful into establishing the detail of what parents wanted from their encounter with the health service and contribute to future service planning. However, it was found that few parents could articulate specific expectations beyond having to wait, but they valued the reassurance that their child would be guaranteed a medical assessment.

5) To establish parental perceptions of the outcome of the encounter, and how expectations matched their experience.

While parents were not found to have definite expectations regarding quality of care, they were able to recognise factors that made their encounter with the health service a positive or a negative experience.

6) To gain insight into what service parents would like to access when their child is unwell.

Parents wanted their child to be reviewed quickly and did not want to wait. They did not want to battle through a complex health system, but to access a simple service when their child was unwell. While parents appreciated a child-focused environment, they wanted the HCP to listen and acknowledge their position as a parent. It was the time taken by the HCP to communicate with parents which conveyed confidence in their expertise and reassured parents the most.

7) To identify potential strategies to impact positively on parental experience and service development.

Drawing from the findings of the study, a model has been proposed that co-locates a dedicated paediatric telephone advice service, access to treatment for minor injuries, minor illness and emergency care. Parents would no longer need to select the most appropriate service for their need. Working together on one site would ensure that communication and coordination between services. Care would remain consistent, and parents should not feel criticised for their attendance as the HCP would expect that they should attend if they were concerned about their child.

6.2 KEY MESSAGES FROM THE STUDY

1) This is the first known study that interviewed parents contemporaneously during their visit to the emergency department.

Previous studies have collected data retrospectively. This study captured the decisions that parents made at the point of need as a more accurate representation of what they were experiencing. Their concerns, emotions and frustrations were not tempered or embellished following a period of reflection. This approach to further research would elicit more valid data and promote better decision-making on service design.

2) The study found that the interaction with the HCP exerted a significant effect on the parent's experience and their help-seeking behaviour.

A negative encounter often led to the parent returning to the health service to seek further help for their child. Participants frequently described interactions with a HCP which left them feeling dismissed or criticised. Parents failed to achieve what they wanted from the encounter after they sought help but were turned away. They wanted to feel that the HCP was engaged meaningfully and recognised the significance of their role as a parent and the status of their child as an individual. The continued imbalance of power felt by the parent when relating to the HCP was highlighted. Conflict was seen between the two perspectives of the HCP and the parent over the purpose of the health service. For services to be provided and utilised efficiently, there has to be unity of purpose. This finding led to the consideration of social theory as a method of exploring the power of structure and its relationship with human behaviour.

3) The application of Giddens Theory of Structuration was novel in exploring the social relationships between parents and the HCP working within the structure of health care.

This made sense of the psychosocial influences on help-seeking together with parents’ interrelation between social rules and their subsequent thoughts and action. Parents responded to their instinctive concern for the welfare of their child while generally conforming to the rules of the separate structures of parenthood and health. This is important as it recognises how parents adapt and develop their help-seeking behaviour in response to their interface with the health structure and the HCP working within that structure.

4) The study recognised the HCP as a powerful agent controlling access to resources and knowledge but who was influenced by pressures and targets within the health service.

The HCP holds the power to enable the parent to access the resources of the health structure. Through interaction, the HCP conveys the rules, and parents must attempt to regulate their behaviour accordingly. As the HCP responds to the changing expectations of performance targets rather than the expectations of the parent, the rules change. The HCP anticipates that the behaviour of parents should comply with newly modified rules of the health structure. If the parent does not do so, criticism is levied, and the power of the HCP is reinforced. Following a period of reflexivity, parents may approach future encounters feeling vulnerable to the risk of criticism. Alternatively, parents may develop greater confidence in approaching health services should they perceive the HCP to have acted in such a way as to erode their trust. As a result, the power of the HCP is reduced. This is an important finding since the agency of the HCP and the health structure were seen to influence parents’ ongoing agency with health services should their child fail to receive the level of care for which the parent had hoped.

5) The NHS is a complicated system that parents tried to navigate, but they were thwarted by its complexity and conflicting messages.

Parents had responded to the message to choose the right service to meet their health needs but found the options difficult to navigate. Services were not designed with the child and family in mind, so parents were destined to fail. The system created delays which increased parental anxiety and led to frustration. They experienced difficulties in gaining access to appointments, limited continuity of care, and confusion about which service to use. Amongst the complexity of available options, the simplest and safest service to understand was the route into the emergency department. Parents were frequently advised by other healthcare services to attend the emergency department which made parents question the usefulness of these services when they might as well have attended the emergency department directly. Significantly, the study found that the current structure of the health service perpetuates the pressures that it is currently experiencing, including the persistent rise in attendance at the emergency department.

6) Parents were able to disregard the rules of the health structure if they were sufficiently worried about their child.

For parents of unwell children, the process of reflexivity led to an evaluation of the competence and rules of the health structure based on their experiences. Previous encounters with the health service saw parents monitor and revise their actions and they began to work outside the discursive rules of the structure. Their concern for their child overcame the difficulties that they encountered as they sought help from another source or returned until they felt satisfied with the care that their child received. It is important for the health service to respond positively and effectively at the first encounter, reducing the need for parents to seek further help.

7) The study found that the features of an illness that led to parental concern were consistent.

A significant finding from the study was that the main triggers and symptoms of illness that induce parental concern have not changed since the historic findings from the study by Kai in 1996. This is despite the advocacy of parental education and attempts to improve health information (Butun & Hemingway, 2018; Holden et al., 2017; Watson & Blair, 2018). Future service design should accept and accommodate the fundamental and unchanging features that drive parents to seek help.

8) When their child is unwell parents wanted a service that was available, simple to access, and that offered a standard of care that reassured and empowered them to continue to care for their child.
Parents equally wanted a service that was kind and compassionate, with the time to consider the needs of the child and parent in their entirety.

6.3 CONCLUSION

This study has challenged the assumptions or conclusions of previous studies that have apportioned blame to parents for the ‘inappropriate’ or overuse of the health service. Instead, it shifts the blame by identifying the culpability of HCPs and the healthcare system in generating the rise in the demand for urgent care. It has acknowledged that it is the current array of urgent care services that are ‘inappropriate’, designed by HCPs with little curiosity over the nature of healthcare that parents want to access when their child is unwell. The sustained rise in the attendance at the emergency department shows that, unless the right healthcare service is made available, parents will continue to experience frustration, criticism, and seek help until they receive what they want on behalf of their child.

Alternatively, services for children that are designed to offer simple and timely access to expertise at one location and accommodate all severities of illness would relieve some of the anxiety that parents experience when their child is unwell. Interagency referrals should reduce and, once parents are successfully reassured and able to continue to care for their child, they should no longer feel it necessary to seek further help. It is anticipated that this model of urgent care for children will be cost effective and lead to a reduction in the numbers of children accessing emergency care for a mild to moderate acute illness.

The study has focused only on gaining insight into a parent’s experience as a help seeker on behalf of their child within the health service. Future studies will focus on the experience of the HCP, in particular the HCP within a primary care setting, to investigate the pressures they experience and to consider service changes that improve the working relationship between the HCP and the parent.

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APPENDICES

APPENDIX A: Search History

Search carried out in CINAHL and MEDLINE via EBSCO 2005 onwards; title and abstract, peer reviewed, research, English language.
Date of search 11.07.19

No.	SEARCHES	
S1	Child* OR Infant OR Paed* OR P*ediatric	272,343
S2	Unwell OR Sick OR Ill* OR fever*	21,957
S3	Mild OR Non-urgent OR inappropriate OR unecessary	26,975
S4	Parent OR Carer OR Famil* OR mother OR father, of a child* with illness	159,187
S5	Concern OR Worry OR anxious OR Expect* OR influence	40,725
S6	Emergency department, Accident and Emergency, A&E, urgent care, inappropriate attendance	51,090
S7	Experience OR satisfaction	159,830
S8	S1 AND S2 AND S3	71
S9	S4 AND S5 AND S6	366
S10	S8 AND S9	0
S11	S1 AND AND S2 AND S4 AND S6	89 (Parental concern and bringing their mildly unwell child to the ED)
S12	S4 AND S6 AND S7	38 (Experience and satisfaction)

Search carried out in British Nursing Index via ProQuest, 2005 onwards; abstract, peer reviewed, English language.
Date of search 18/07/19

S1	Child* OR Infant OR Paed*	48,976
S2	Unwell OR Sick OR Ill*	21,957
S3	Mild OR Non-urgent OR inappropriate OR unecessary	7,313
S4	Parent OR Carer OR Famil*	46,712
S5	Concern OR Worry OR anxious OR Expect*	18,948
S6	Emergency department OR A&E OR Urgent	19,224
S7	Experience OR satisfaction	62,583
S8	S1 AND S2 AND S3	129
S9	S4 AND S5 AND S6	276
S10	S8 AND S9	23
S11	S1 AND AND S2 AND S4 AND S6	126
S12	S4 AND S6 AND S7	3

Search carried out in Cochrane Library, 2005 onwards; abstract, peer reviewed, English language.
Date of search 18/07/19

MeSH descriptors for Child* mild illness OR Parent AND emergency department attendance	36 Cochrane reviews 628 Trials
	1 study located; Lower urgency paediatric injuries: parent preferences for emergency department or general practitioner care

Search carried out in Google Scholar, 2005-2019. Various search terms used specific to the question.
Date of search 18/07/19

Bringing a child to the emergency department with non-urgent illness	14 papers identified after excluding duplicates
Expectations/satisfaction of parents bringing child to the emergency department	
Paediatric emergency department attendance with non-urgent illness	

TOTAL STUDIES FOUND – 89 + 126 + 1 + 14 + 6 + 41 = 277
(S11 + S11 + 1 COCHRANE + 14 GOOGLE + 6 REFERENCES (+ 41 RELATING TO SATISFACTION)

Duplicates removed 146
Adult focused research 35
No full text available
Expert opinion, review articles and policies 28
No reference to parental perspective 25
Condition specific e.g asthma 5
Reference to emergency admissions rather than attendance 13

Reduced down to 18

APPENDIX B: Example/Excerpt From Casp Tool

CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of Qualitative research

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship Yes between researcher and participants been adequately considered?

Section B: What are the results?

7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?

Section C: Will the results help locally?

10. How valuable is the research?

APPENDIX C: University research ethics approval confirmation

University of Salford
MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

Doctoral & Research Support
Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
Manchester
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk

11 January 2019

Dear Ruth,

RE: ETHICS APPLICATION HSR1819-031 – ‘Bringing your child to the accident and emergency department; a study of parental expectations and experiences.’

Based on the information that you have provided, I am pleased to inform you that your application HSR1819-031 has been approved to go forward to NRES (HRA).

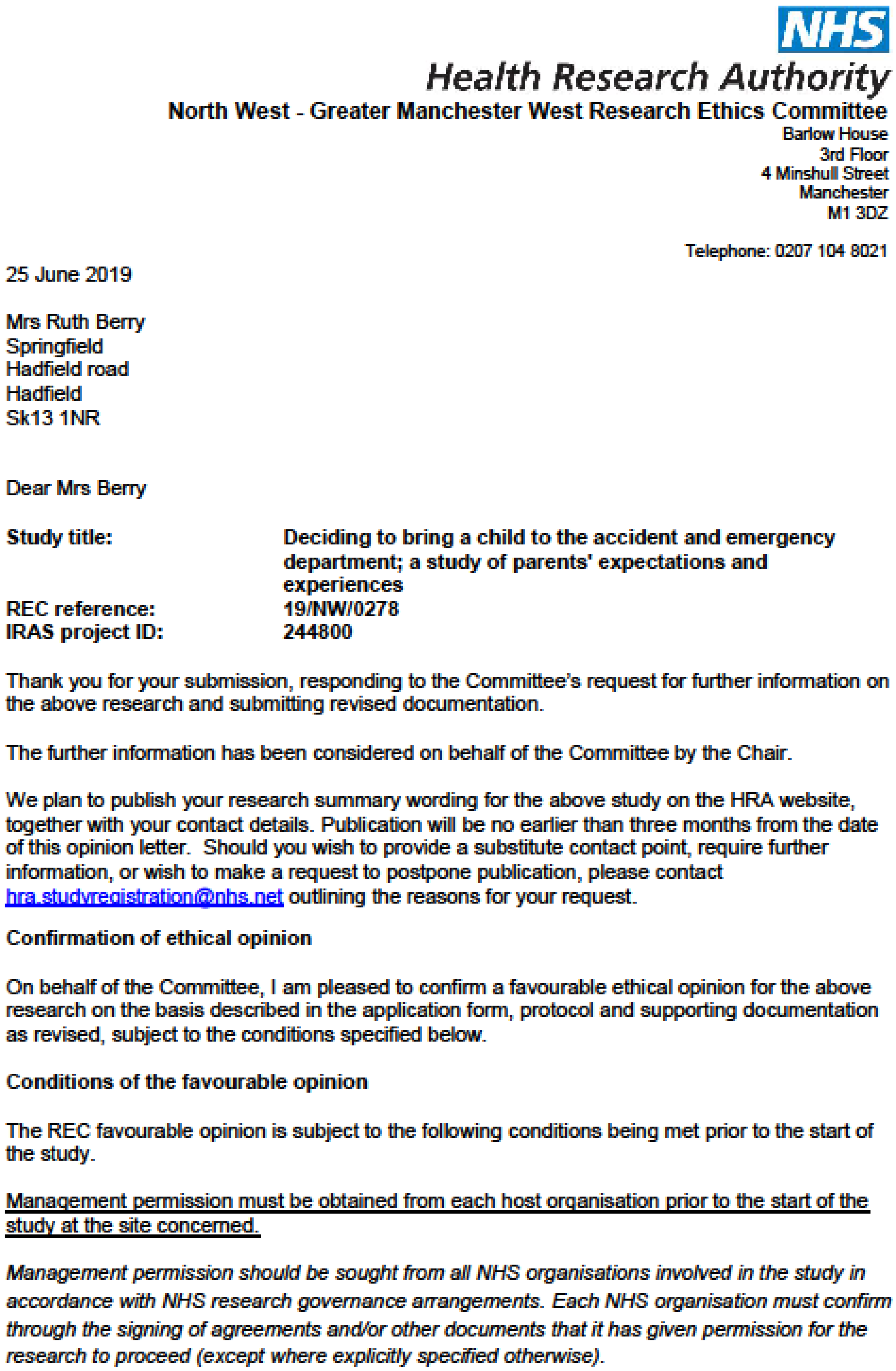
Once you have received it, please submit a copy of the NRES (HRA) approval letter to Health-ResearchEthics@salford.ac.uk so that it can be placed on your application file.

If there are any changes to the project and/or its methodology, then please inform the Health Research Ethics Support team as soon as possible.

Yours sincerely,

Professor Sue McAndrew
Chair of the Research Ethics Panel

APPENDIX D: NHS REC approval letter



NHS
Health Research Authority
North West - Greater Manchester West Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8021

25 June 2019

Mrs Ruth Berry
Springfield
Hadfield road
Hadfield
Sk13 1NR

Dear Mrs Berry

Study title: **Deciding to bring a child to the accident and emergency department; a study of parents' expectations and experiences**
REC reference: **19/NW/0278**
IRAS project ID: **244800**

Thank you for your submission, 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.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Appendix E: PARTICIPANT INFORMATION SHEET

(Version 2, 28/05/2019) (IRAS Project ID 244800)

Bringing your child to Accident and Emergency department: a study of parents’ expectations and experiences

You are invited to take part in a research study taking place in the children’s accident and emergency department. You are free to decide whether or not to take part in the study, and your decision will not affect the care of your child in any way. Before you decide to take part, it is important for you to have all the information so you know what it will involve for you. Please ask if you require any further information about the study.

WHO IS UNDERTAKING THE RESEARCH?

My name is Ruth Berry. I work as an Advanced Paediatric Nurse Practitioner in the accident and emergency department and I am currently undertaking a doctorate at the University of Salford.

WHAT IS THE PURPOSE OF THE STUDY?

A number of healthcare services are available when children are ill, including the GP practice, walk-in centres, NHS helplines and pharmacies. Knowing which service to choose when a child is unwell can be difficult and many families opt to bring their child to an emergency department.

This study will explore the circumstances around parents’ and carers’ decision to bring their child to the accident and emergency department and their initial expectations of their visit. This will then be compared with their actual experiences of visiting the department. It is anticipated that the findings from this study will help to inform and modernise local healthcare services so they are better designed to meet the needs of families when a child is unwell. The study findings will be included in a doctoral thesis submitted to the University of Salford.

WHAT WILL HAPPEN IF I AGREE TO TAKE PART?

Once your child has been assessed and has received treatment, I will ask you questions about your decision to attend the department and what your expectations of the visit were. This will typically take 10 minutes. Subject to your consent, written notes will also be taken throughout the discussion and checked for accuracy with yourself on conclusion of the interview. You will then be contacted by telephone 48 hours later when you have had time to reflect on your visit, to enable you to comment further on your experience in the department. Written notes will also be taken during the telephone conversation and then checked for accuracy with yourself. If unable to contact you by telephone on the first occasion, a further attempt would be made once more that day and once again over within the next 2 consecutive days. The contacting number will appear as 0161 922 4444 (this number does not receive return calls).

If you are later unable to take part in the telephone interview, information from the first interview undertaken in the department will still be included in the study unless you choose to withdraw.

DO I HAVE TO TAKE PART?

No. It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. **This will not affect the standard of care your child receives whilst in the department afterwards**.

WHAT ARE THE ADVANTAGES OF TAKING PART?

You and your child may not benefit directly from taking part in this study. Your opinion is valued and we hope the findings from the study will help to inform health services of what is required to meet the changing needs of families when a child is unwell.

WHAT ARE THE DISADVANTAGES OF TAKING PART?

We anticipate no risk to you in taking part in the study. The only additional burden will be your time to complete the interview and telephone follow up 48 hours later. Talking about what happens when your child is ill can be upsetting. If you feel upset, the nursing staff in the department will provide support. In the unlikely event that further support is needed, staff can signpost you to organisations which can offer help in the longer term (details at the end of this information sheet).

WHAT WILL HAPPEN TO THE INFORMATION THAT IS COLLECTED?

All information collected during the course of the research will be kept strictly confidential. I will ask for your name and telephone number so that I can call you two days later for you to tell me what your experience was like in the department. This information will be kept securely on a password-protected computer to which only I have access. It will not be possible to identify you or your child in any reports, presentations or publications that result from the research study. As part of my duty of care, an exception to confidentiality will occur should the interview disclose any poor practice, safeguarding or child protection concerns. The data will be excluded from the research and information will be shared with other agencies to protect the welfare of the child and family. The study data will be kept securely for two years after the end of the study, though, provided that you agree, it will be kept in an anonymised form for further use in research.

WHAT WILL HAPPEN TO MY DATA IF I WITHDRAW FROM THE STUDY?

If you wish your data to be destroyed, you need to inform the researcher of your withdrawal within one month of being interviewed. After that point it will already have been incorporated with other parents' contributions and could not be extracted. If you let me know that you no longer wish to take part by telephone or email, I will ensure that you are not contacted again for the study. You would not need to provide a reason for your decision. If you wish to know the outcome of the study, a summary will be available on request.

WHO HAS REVIEWED THE STUDY?

All research in the NHS is reviewed by a designated NHS research ethics committee to protect your interests. This study has been reviewed and given a favourable opinion by one of these committees. The study has also been reviewed by the research ethics committee at The University of Salford.

NEW REGULATIONS ABOUT THE USE OF YOUR DATA

As an NHS organisation we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the
UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact the University of Salford Data Protection Officer who will investigate the matter: Andrew Hartley, Director of Legal and Governance, 0161 295 2045, a.hartley2@salford.ac.uk, Maxwell Building, University of Salford, Salford M5 4WT.
If you are not satisfied with the response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office.

The researcher as part of the NHS trust will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from NHS regulatory organisations may look at your medical and research records to check the accuracy of the research study. The supervisor from the University of Salford who will help to manage the study and analyse the interview data will not be able to identify you and will not be able to find out your name or contact details.

The University of Salford will keep anonymised data used in the analysis from this study (but NOT any of your personal data) after the study has finished in case it can be helpful for further research to make care in A&E departments better. No details of you or your child will part of this. Once the study has been completed and the researcher's doctorate has been examined and awarded, the NHS trust will destroy the personally identifiable data held about you.

CONTACTS FOR FURTHER INFORMATION OR IN CASE OF CONCERN
If you would like to discuss the study, please contact the researcher

- Ruth Berry: ruthj.berry@tgh.nhs.uk 0161 922 4861

If you would like to discuss any concerns with the doctoral supervisor

- Professor Tony Long: t.long@salford.ac.uk 0161 295 2750

If the matter is still not resolved, please forward your concerns to Professor Susan McAndrew, Chair of the Health Research Ethical Approval Panel, Room MS1.91, Mary Seacole Building, Frederick Road Campus, University of Salford, Salford, M6 6PU. Tel: 0161 295 2778. E: s.mcandrew@salford.ac.uk

If you wish to complain formally, you can contact the Patient Advice and Liaison Service (PALS) at Tameside General Hospital 0161 922 4466 or by emailing palsandcomplaints@tgh.nhs.uk

Thank you for taking the time to read this information sheet

Appendix F: Consent Form

PARTICIPANT CONSENT FORM

(Version 2, 28-05-19) (IRAS Project ID 244800)

Participant Identification Number: _____

Bringing your child to Accident and Emergency department: a study of parents' expectations and experiences

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Researcher: Ruth Berry, Advanced Paediatric Nurse Practitioner, TGH
Supervisor: Professor Tony Long, University of Salford

Please read the statements and initial the boxes if you agree.

1. I confirm that I have read the information sheet (version 1, 01-04-19) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my child's medical care or legal rights being affected. ☐

3. If you wish your data to be destroyed, you need to inform the researcher of your withdrawal within one month of being interviewed. ☐

3. I understand that participation will involve an informal interview with the researcher in the department, and I give permission for written notes to be taken during the interviews. ☐

4. I give permission for a follow up interview via telephone and consent to my name and telephone number being stored for this purpose. ☐

5. I have been assured that no personally identifying details (such as my name) will be included in any reports or publications. ☐

6. I understand that the data that I provide will be stored securely and confidentially by the researcher at the University and used only as stated in the information sheet. ☐

7. Since there will be no identifiable details, I understand the data may be stored for use in further studies. ☐

8. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from Tameside NHS Foundation Trust, or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐ ☐

9. I agree to take part in the above study. ☐

______________________	___________________	___________________
Name of Participant	Date	Signature
______________________	___________________	___________________
Name of Researcher	Date	Signature

APPENDIX G: Excerpt from thematic analysis framework

THEMATIC ANALYSIS (Excerpt)		
THEME		
	PARENTAL FEELINGS OF CONFLICT – links with JUDGEMENT	012, 014, 017
CODE		**INTERVIEW NO.**
1.	CRITICISM (PARENTAL FEELINGS OF) *sensitivity, fear, factors that will overcome* *JUDGEMENT?* **001** Paradoxical position of apologetic for their perceived inexperience and help seeking. Yet driven to continue to seek help until they get what they want – which is? ‘Needing to know so they can manage the problem’. How do they overcome this conflict Conflict of determination to do the right thing; use NHS appropriately, balance risk, care for their child, appease the family. Risk criticism **Int 012** Mum said her worries today were wasting the time of ED, plus her own time as they were here for 6 hours last time. Mum said how “I don’t want to be seen to waste their (A&E) time, especially after what the (A&E) doctor said we shouldn’t have come last time” *(despite the sensitivity to criticism, she was prepared to risk this to push for her daughter to receive treatment and exclude a ‘serious problem’ – see above)* Mum recognizes the pressures the NHS face – and that it ‘belongs to everybody’ and they do not want to waste resources. (*By saying ‘it belongs to everybody’ does she feel there limited resources to be distributed – mum is uncertain if they are ‘wasting resources’ but is torn in wanting her daughter to receive treatment – she doesn’t know if it’s serious or not, she is in a state of CONFLICT, almost guilt, driven by criticism, not getting the help/assurance they need, long duration of illness, impact on family life/school etc. Now concerned about child’s MH).*	001, 004, 008, 011, 012, 013, 014, 018, 019

	Int 013 Dad, as a paed nurse had higher expectations but said how there is ‘an element of choosing your battles’ as he “kept quiet for the sake of good relationships and to not risk compromising the care of my child.” *Does he feel more vulnerable, or recognize his child is vulnerable and will put aside own feelings to ensure his child is treated well.* He would certainly speak out if he felt care/treatment was wrong	
2.	CHALLENGE AUTHORITY **Int 17** Pharmacy advised NHS111 who advised they would usually send to A&E but weren’t doing this at present due to Corona Virus and had to assess the risk. They rang back in half hour and advised attendance however mum said she “would have come anyway as I’d decided the risk of meningitis was greater for her than the risk of COVID.” She knew that children didn’t seem to get too unwell with COVID	013, 014, 017, 023
3.	JUDGEMENT **Int 04** Mum; “I feel we are judged, as soon as you say ‘we’re first time parents’…” She expressed concern “I might be being a bit ‘dramatic.” She paused “But as he’s only a 7-week-old baby, I’m prepared to be dramatic.” Dad was less concerned “I just wanted him to be seen’” **Int 11** Mum described how she finds GP’s who she is less familiar with are quick to dismiss her concerns, as she is a young mum. She feels ‘fobbed off’. **Int 014** Whenever she sees the GP with one of the children, she gets the feeling they are thinking ‘she’s back again’. (*What conveys this message to mum leaving her feeling criticised, time waster, uncomfortable compared to almost relief when she is listened to, her concerns considered and her child examined thoroughly – mum is clearly wanting the assurance of a complete examination to provide reassurance that everything has been considered*	001, 004, 010, 011, 012, 024

4.	INDIFFERENT TO CRITICISM/JUDGEMENT **Int 10** When asked about being made to feel like a worried parent, “not at all”. “Totally no concerns”. *Why? Is her peer support enough to give her confidence? Has her previous negative experience given her confidence because the HCP doesn’t always get it right so they have lost power to criticize.* Is there a subculture of just seek medical help regardless of the HCP opinion or pressure on services.	010, 013. 019, 024
5.	CONVENIENT/UNCONCERNED/EASIEST OPTION	008, 010, 011
THEME		
6.	**JUSTIFICATION** **009** Family all felt their concerns were **justified** and felt he needed to be seen in ED Father went on to say how their own visit “was appropriate due to his age” (rather than the presenting illness).	010
CODES		
7.	JUSTIFICATION/ ADVISED BY HCP TO ATTEND 001 – advised to attend – no quotes *006* NHS111 – call ambulance, parents no longer feel this is necessary but “felt we had to come as we have been told to come. No choice really.” 011 “The GP told me to come. If it had been a different GP, I probably wouldn’t have trusted them, but this GP is really good and I agreed with her.” 012 “I always feel justified in coming as I get advice first. I’ve never just made the decision myself to come.”	001, 002, 003, 004, 009, 011, 017, 018, 021, 024, 028