

# 1 Navigating uncertain illness trajectories for young children 2 with serious infectious illness: a mixed-methods modified 3 grounded theory study.

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## 27 Abstract

28 Infectious illness is the biggest cause of death in children due to a physical illness, particularly in  
29 children under five years. If mortality is to be reduced for this group of children, it is important to  
30 understand factors affecting their pathways to hospital.

31 The aim of this study was to retrospectively identify organisational and environmental factors, and  
32 individual child, family, and professional factors affecting timing of admission to hospital for children  
33 under five years of age with a serious infectious illness (SII).

## 34 Methods

35 An explanatory modified grounded theory mixed methods design was used in collaboration with  
36 parents. Two stages of data collection were conducted: Stage 1, interviews with 22 parents whose  
37 child had recently been hospitalised with a SII and 14 health professionals (HPs) involved in their pre-  
38 admission trajectories; Stage 2, focus groups with 18 parents and 16 HPs with past experience of SII  
39 in young children. Constant comparative analysis generated the explanatory theory.

## 40 Findings

41 The core category was 'navigating uncertain illness trajectories for young children with serious  
42 infectious illness'. Uncertainty was prevalent throughout the parents' and HPs' stories about their  
43 experiences of navigating social rules and overburdened health services for these children. The  
44 complexity of and lack of continuity within services, family lives, social expectations and hierarchies  
45 provided the context and conditions for children's, often complex, illness trajectories. Parents  
46 reported powerlessness and perceived criticism leading to delayed help-seeking. Importantly,  
47 parents and professionals missed symptoms of serious illness. Risk averse services were found to  
48 refer more children to emergency departments.

## 49 Conclusions

50 Parents and professionals have difficulties recognising signs of SII in young children and can feel  
51 socially constrained from seeking help. The increased burden on services has made it more difficult  
52 for professionals to spot the seriously ill child.

## 53 Keywords

54 Serious infectious illness, illness trajectories, parents, children under 5 years, uncertainty

## 55 Background

56 Infection is a major cause of childhood deaths in the UK and globally, particularly in the under 5 year  
57 age group. The most recent analysis of child mortality data (from 2013-15) in England and Wales  
58 found that infection was associated with 20% of all childhood deaths (1). Child Death Reviews (CDR),  
59 which aim to identify modifiable factors in any child's death, are reported by Local Safeguarding  
60 Children's Boards and have been collated into annual reports for England by NHS Digital since 2018  
61 and previously by the Department for Education (2). In the year ending March 2019, modifiable  
62 factors were identified in 30% of all child deaths (compared to 24% in 2016 (3)) and 38% of deaths  
63 from infection (4), suggesting that more can be done to prevent these deaths.

64 Emergency admissions and emergency department (ED) visits have continually increased over the  
65 last 20 years. Between 1999 and 2010 emergency admissions increased particularly for under 5 year  
66 olds (<1 year by 52%, aged 1–4 years by 25%) and acute infections (by 30%) (5). This trend continued  
67 between 2007 and 2017 with a 1.6%/year increase in ED visits for all children and 3.9%/year for  
68 infants (6). In one Midlands region in the UK, 28,929 children (27.9% of all admissions) were  
69 admitted with infectious illness between 2011-2014, the largest group of emergency hospital  
70 admissions by International Classification of Diseases (ICD) coding (7). There is no single code

71 available to indicate serious infectious illness (SII) – the focus of this paper – making it difficult to  
72 determine the exact pattern of attendance or admissions for children diagnosed with a SII.

73 More problematic is determining how many children’s serious illness could have been recognised  
74 sooner in primary care. These cases where the seriousness of these children’s illnesses was missed  
75 should be reported as patient safety incidents through the National Reporting and Learning System  
76 (NRLS); however, there are few reports submitted to the NRLS from primary care leading to limited  
77 learning about influences on pre-hospital care. These systems depend on recorded data;  
78 consequently, human factors are rarely captured. Notably, families’ perspectives are absent from  
79 the data collected and parents report difficulties in securing the engagement of health services in  
80 learning from their children’s deaths ([www.mothersinstinct.co.uk](http://www.mothersinstinct.co.uk)).

81 The aim of our study was to retrospectively identify organizational and environmental factors and  
82 individual child, family and professional factors affecting timing of admission to hospital for children  
83 under 5 years of age with serious infectious illness (SII) in two counties in the United Kingdom. Our  
84 research questions were:

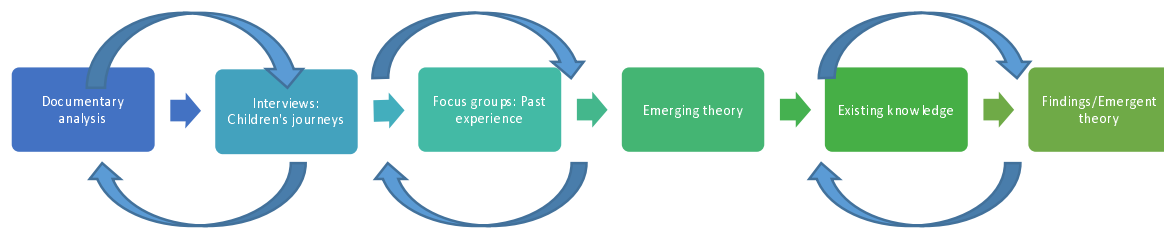
- 85 1. What, if any, social and/or personal child and family characteristics influence the journeys of  
86 children with serious infectious illness from home to hospital admission?
- 87 2. What, if any, modifiable organizational, environmental and individual human factors within  
88 health services affect the timing of the journeys of children with serious infectious illness  
89 from home to hospital admission?

## 90 Methodological approach

91 Working with parents we co-designed a modified grounded theory (8, 9) explanatory, mixed-  
92 methods study (See Fig 1). Each step influenced the next and vice versa until a core category and  
93 theory which explained the findings was identified. At this stage the emerging theory was compared

with existing knowledge to explore how extant evidence fitted and to identify new knowledge. This process generated our emergent theory and our findings.

*Figure 1 Explanatory mixed methods modified grounded theory design*



## Method

Two study areas were selected for the project representing a population served by a District General Hospital (DGH) and a Teaching (Tertiary) Hospital (TH). These two areas included patterns of service provision and population demographics similar to that in England as a whole. Ethics approval was granted by East Midlands – Nottingham 1 Research Ethics Committee (17/EM/0334) on 8<sup>th</sup> November 2017.

Our first step was to gather available documentary evidence in each of the two study areas to provide the context for the research. The aim of this stage was to:

- identify known modifiable organizational, environmental and human factors from reports concerned with child deaths;
- gather data on patterns of service use from Hospital Episode Statistics (HES) data and ambulance service data for the preceding two years; and
- map the services available to children.

No information was available to the study team concerning learning from child death reviews in either area, consequently we were not able to analyse our data for any related information. Urgent

115 and emergency care services were identified in each study area from health service webpages.  
 116 Coding used to categorise ambulance service use for children with acute infections was identified in  
 117 collaboration with ambulance service staff so that the number of calls in each area could be  
 118 identified for these children for the years 2015/16 and 2016/17. A researcher (KWD) worked with  
 119 Principal Investigators (PIs) for each area to identify relevant HES coding for children presenting to  
 120 hospital with a serious infectious illness so that data from the two hospitals could be compared.  
 121 These codes are based on diagnostic classifications and record an episode of continuous care,  
 122 consequently the data does not identify the numbers of children but does provide data on the level  
 123 of activity in each hospital. Data were analysed using descriptive statistics to identify any differences  
 124 between the two study areas. For further information on the documentary analysis please see S1  
 125 Fig.

126 Our next steps were to undertake data collection in two stages. Stage 1 involved in-depth interviews  
 127 with families whose child had recently been treated for a SII in one of the two hospitals in our study  
 128 area and the health professionals involved in their pre-hospital admission journeys. Stage 2 involved  
 129 focus groups with parents (recruited nationally) and professionals (recruited in the area surrounding  
 130 the two study sites) who had experience of child(ren) with SII between 2011 and 2018. Parents  
 131 recruited to the focus groups provided data concerning their memories of these traumatic events  
 132 and how these longer term memories had influenced their future health service use. HPs in Stage 2  
 133 were all in clinical practice at the time so had recent and longer term experiences to share.

134 These stages aimed to provide a comprehensive examination of the journey children with a SII  
 135 travelled from falling ill at home to being admitted to hospital. We included families with children  
 136 under 5 years of age who had had a SII, excluding neonates less than 28 days of age, post-neonatal  
 137 babies who had never left hospital, children who died at home, children in receipt of palliative care  
 138 or whose death was expected prior to the infection and children living outside either hospitals'  
 139 catchment areas. We were unable to identify a pre-existing definition for SII to adopt for our study.

Consequently, based on expert opinion of clinicians in the study team (DR, EC, PP), within this study we considered children to have had a serious infectious illness if they had received care on a paediatric intensive care (PICU) or high dependency unit (HDU) for a minimum of 48 hours with a diagnosis of infection. Our methods and approaches were guided by our parent collaborators.

## Recruitment

In Stage 1, families were recruited between January and 2018 and Oct 2019 and March 2019 in the hospital setting by clinical research nurses once their child was improving and had been transferred from PICU/HDU to a children's ward: three from the DGH and nine from the TH. These families were followed up by phone at home after discharge from hospital, by member of the research team (SN, KWD). Informed consent was obtained face-to-face at the beginning of the interviews. All the family member participants were parents or primary carers of the children concerned. Throughout this paper the term parent is used to refer to all of the parent and carer participants. During the interview, parents were asked for permission to contact the health professionals involved in their child's care. These professionals were then contacted by a researcher (KWD), given information about the project and invited to take part in the project.

Parent participants in Stage 2 were recruited through a local parent panel, by word of mouth and Facebook and through our charity partners between May and October 2019. Posters and leaflets for GP practices disseminated through primary care networks generated no interest. Health professional participants were recruited by members of the research team (DR, KWD, PP) and the local clinical research network by email and word of mouth.

## Data collection

The first stage of data collection involved retrospective in-depth interviews with parents of children under 5 years whose child had been discharged from hospital within the last 4 weeks following

treatment for a serious infectious illness (SN, KWD). These audio-recorded in-depth interviews were conducted in the family home. Parents were asked to *‘Tell me the story of your child’s illness from the time you first noticed something was wrong up until they were admitted to hospital?’* followed by neutral prompts to help them tell us more about their experiences.

We then interviewed HPs who had been involved in these children’s pre-hospital journeys. All the HPs were interviewed by KWD in person within a quiet room in their workplace. Each HP was asked to *‘Tell me the story of the child’s illness during the time they were in your care’* followed by neutral prompts to generate further detail.

The second stage of data collection involved three focus groups with parents whose child had had a SII between 2011 and 2018 from across the UK in locations away from health services. A further three focus groups were held in hospital seminar rooms with HPs from the area surrounding the study sites who had experience of caring for such children in first contact services during the same time period. Each focus group was audio-recorded and facilitated by two people from the research team (KWD, SN, TB) and on one occasion a clinical research nurse from the TH. Parent focus groups were asked the starter question: *‘Thinking back about your child’s illness, what helped or prevented you getting them admitted to hospital quickly?’* Health professional focus groups were asked a similar starter question: *‘What do you think are the key factors influencing the timing of admission to hospital for children with serious infectious illness?’*. These questions were followed by a series of questions that had arisen from analysis of the Stage 1 data creating a semi-structured discussion.

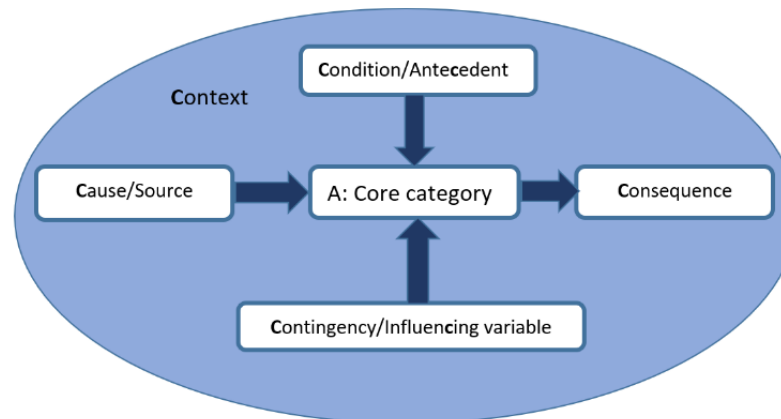
## Data analysis

Data were analysed inductively (no a priori coding) using the constant comparative method (10), including line by line coding facilitated through the use of QSR NVivo 11 and drawing timeline diagrams depicting each child’s pathway to hospital admission (SN, LB). Data from our documentary analysis were combined with the analysis of the interview and focus group data – in Glaserian



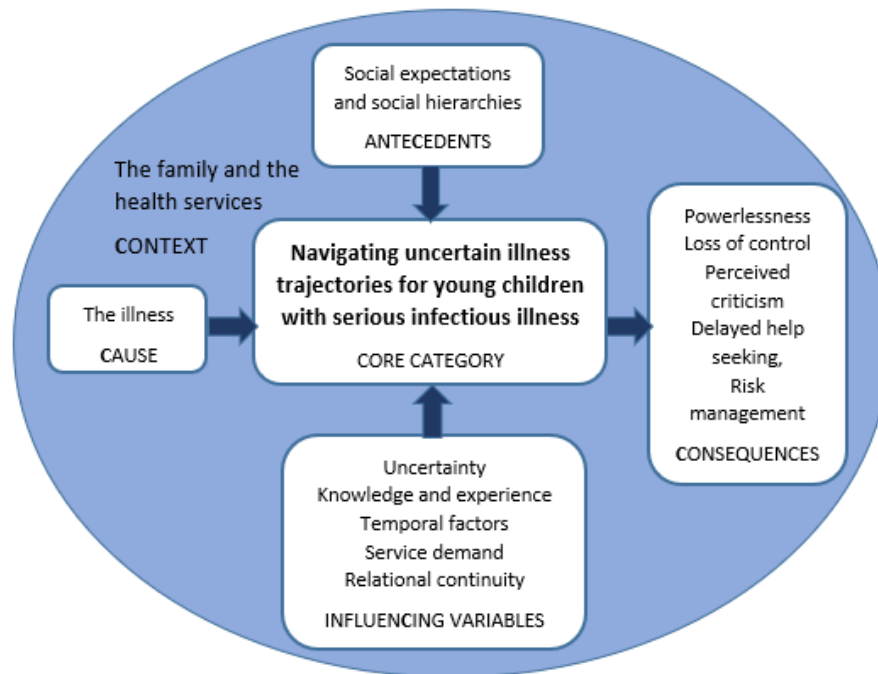
grounded theory both qualitative and quantitative data can be used to develop theory reflecting Glaser's mantra '*all is data*' (11 p145). Glaser's 6 Cs coding frame (8) facilitated the identification of, and interrelationships between, factors influencing children's pathways. In common with most grounded theory research projects, we did not identify any covariances (when two variables change at the same time), making ours a 5 Cs model of Context, Conditions/Antecedents, Causes, Contingencies/Influencing variables and Consequences, all of which related to A, the Core category (Fig 2).

Figure 2 5C's coding family adapted from Glaser's 6Cs



A core category is central to the data, accounting for a large proportion of the variation in behaviour as all the other categories are related to it within, what is now, the identified theory (8, 10). Once the emerging theory had been identified, its fit with existing knowledge (12), including our systematic literature review (13), was explored. Saturation was considered to have been achieved as '*the theory is abstract and linked to the literature, the findings are generalizable to new incidents, and the findings surprise and delight the reader.*' (14). The outcome of this final process is the theory represented in Fig 3 'Navigating uncertain illness trajectories: relationships between categories'.

**Figure 3 Navigating uncertain illness trajectories: relationships between categories**



## Findings

### Study participants

A total of 70 individual participants were recruited to the project between January 2018 and October 2019. In Stage 1 twelve families (a total of 22 parents), three from the DGH and nine from the TH (Table 1), and 14 health professionals (Table 2) were recruited.

**Table 1 Stage 1 Characteristics of parent/carer participants and their affected child (N=22~)**

Characteristic	Number of parents (%)	Characteristic	Number of parents (%)
<b>Age</b>		<b>Relationship to the child</b>	
25-29 years	3 (13%)	Parent: Mother	11 (50%)
30-39 years	10 (44%)	Parent: Father	8 (36%)
40-49 years	0	Other family carer	3 (14%)
50-59 years	1 (4%)		
60+ years	3 (13%)		
<b>Gender</b>		<b>Income</b>	
Female	12 (52%)	Less than 10,000	3 (13%)
Male	9 (39%)	10,000-19,999	5 (22%)
<b>Ethnicity</b>		20,000-29,999	4 (17%)

White British	12 (52%)	30,000-39,999	5 (22%)
Indian	6 (26%)	40,000-49,999	0
<b>Employment</b>		50,000-59,999	2 (9%)
Employed (part or full time)	8 (35%)	60,000-79,999	2 (9%)
Unemployed or retired	3 (13%)	80,000-99,999	1 (4%)
Caring for family at home	5 (22%)	100,000+	3 (13%)
<b>Age of affected child*</b>		<b>Diagnoses of affected child*&amp;**</b>	
Under 6 months	1 (8%)	Acute Respiratory	12 (52%)
6-12 months	2 (17%)	Acute exacerbation of recurrent respiratory	5 (22%)
13-23 months	2 (17%)	Acute disseminated encephalomyelitis (ADEM)	1 (4%)
2-4 years old	7 (58%)	Tonsillitis	1 (4%)
		Sepsis and Septicaemia	2 (9%)
~Although 22 parents/carers completed the questionnaire, questions were not compulsory and therefore each question was not always completed by 100% of parents.			
*Based on the number of families (N=12) engaged in Stage 1, not on the total number of parents (N=22) participating in Stage 1.			
**Many children had multiple diagnoses.			

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213 **Table 2 Stage 1 Characteristics of Health professional (HP) participants (N=14~)**

Characteristic	Number of HPs (%)	Characteristic	Number of HPs (%)
<b>Age</b>		<b>Service type**</b>	
21-29 years	5 (36%)	Ambulance Service	6 (43%),
30-39 years	5 (36%)	Emergency Care	8 (57%)
40-49 years	1 (7%)	Other***	2 (14%)
50-59 years	3 (21%)	<b>Job title</b>	
<b>Gender</b>		Emergency Medical Technician	3 (21%)
Female	9 (64%)	Emergency Medical Dispatcher	1 (7%)
Male	4 (29%)	Emergency Medical Consultant	1 (7%)
<b>Ethnicity</b>		Emergency Care Assistant	1 (7%)
White British	11 (79%)	Emergency Care Nurse	2 (14%)
Indian	1 (7%)	Junior Doctor	1 (7%)
Other*	2 (14%)	Paramedic	3 (21%)
<b>Employment</b>		Health Advisor	2 (14%)
Employed (full time)	14 (100%)		
~Although 14 health professionals completed the questionnaire, questions were not compulsory and therefore each question was not always completed by 100% of professionals.			
*Welsh, White other unspecified			
**Some staff work across multiple services			
***Emergency Service - Air Ambulance, Paediatric Ward			

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In Stage 2, a total of 18 parents (Table 3) and 16 HPs (Table 4) were recruited. Health professionals were from our study area, but as local recruitment of parents generated only two participants, we recruited nationally through our charity partners for the parent focus groups. Six parents were unable to attend the focus groups, opting to take part in individual telephone or email interviews.

**Table 3 Stage 2 Characteristics of parent participants (N=18~)**

Characteristic	Number of parents (%)	Characteristic	Number of parents (%)
<b>Age</b>		<b>Relationship to the child</b>	
30-39 years	11 (61%)	Parent: Mother	15 (83%),
40-49 years	5 (28%)	Parent: Father	2 (11%)
<b>Gender</b>		<b>Income</b>	
Female	14 (78%)	Less than 10,000	2 (11%)
Male	2 (11%)	10,000-19,999	3 (17%)
<b>Ethnicity</b>		20,000-29,999	0
White British	12 (67%)	30,000-39,999	0
White other*	3 (17%)	40,000-49,999	1 (6%)
<b>Employment Status</b>		50,000-59,999	1 (6%)
Employed (part or full time)	12 (67%)	60,000-79,999	3 (17%)
Unemployed	1 (6%)	80,000-99,999	4 (22%)
Caring for family at home	3 (17%)	100,000+	2 (17%)
<b>Age of affected child**</b>		<b>Diagnoses of affected child**&amp;***</b>	
Under 6 months	6 (38%)	Acute Respiratory	1 (6%)
6-12 months	4 (25%)	Sepsis and Septicaemia	6 (38%)
13-23 months	2 (12%)	Meningitis	14 (88%)
2-4 years old	4 (25%)		

~Although 18 parents completed the questionnaire, questions were not compulsory and therefore each question was not always completed by 100% of parents.  
 \*European, Scottish, Other unspecified.  
 \*\*Based on the number of families (N=16) engaged in Stage 2, not on the total number of parents (N=18) engaged in Stage 2.  
 \*\*\*Many children have multiple diagnoses.

222 **Table 4 Stage 2 Characteristics of health professional (HP) participants (N=16~)**

Characteristic	Number of HPs (%)	Characteristic	Number of HPs (%)
<b>Age</b>		<b>Service type</b>	
21-29 years	2 (13%)	General Practice	5 (32%)
30-39 years	6 (38%)	Emergency Care	5 (32%)
40-49 years	4 (25%)	Ambulance Service	2 (13%)
50-59 years	4 (25%)	Other**	4 (25%)
<b>Gender</b>		<b>Job title</b>	
Female	9 (56%)	General Practitioner	5 (32%)
Male	5 (32%)	Paediatric Emergency	4 (25%)
<b>Ethnicity</b>		Medical Consultant	
White British	10 (63%)	Emergency Care Children's	1 (6%)
South Asian*	3 (19%)	Nurse	
African	1 (6%)	Community Children's	1 (6%)
Other*	2 (13%)	Nurse	
<b>Employment</b>		Paramedic	2 (13%)
Employed (full time)	12 (75%)	Other***	3 (19%)
Employed (part time)	4 (25%)		
~Although 16 health professionals completed the questionnaire, questions were not compulsory and therefore each question was not always completed by 100% of professionals. *Indian, Pakistani, Bangladeshi ** NHS111, Community ***Community Pharmacist, Dental Hygienist Oral Health Lead, Health Advisor			

## 223 **Navigating uncertain illness trajectories for young children** 224 **with serious infectious illness: The emergent theory.**

225 From the onset of the illness, uncertainty ran throughout parents' and health care professionals'  
226 stories of navigating social expectations and hierarchies and health services to enable these children  
227 to access appropriate treatment in a timely manner. Parents reported trying to navigate multiple  
228 pathways though complex services whilst also having to overcome perceived criticism of their  
229 behaviour and decision making. Health care professionals also reported the need to navigate  
230 complex health services and social hierarchies between professional groups. This uncertainty in  
231 many cases delayed help seeking or referral. If the NHS is conceptualised as a safety net designed to  
232 promote health and prevent avoidable morbidity and mortality, most of the children in this study  
233 have fallen, at least in part, through this safety net.

234 The interrelated sub-categories that make up the emergent theory are presented below with a 'C'  
235 used to highlight which of Glaser's 6 Cs these represent. Categories are presented beginning with

236 'The Illness', the Cause category in grounded theory terms, followed by 'Navigating uncertain illness  
237 trajectories', the Core category to which all the other categories relate, then 'The family and the  
238 health services Context' within which these trajectories took place, the 'Social expectations and  
239 social hierarchies', the antecedents or Conditions, the 'Influencing variables or Contingencies'  
240 affecting these trajectories and finally the 'Consequences' of these complex illness trajectories.

241 Throughout the presentation of the findings, participants are referred to using unique codes (see  
242 Box 1).

#### 243 **Box 1 Participant codes**

Research stage	Type of participant	Code	Additional information
Stage 1	Parents	Study site followed by P for parent and family number (e.g. TH,P01).	Teaching Hospital = TH; District General Hospital = DGH
	Health professionals	HP followed by a number and service identifier such as NHS111/GP/Amb.tech/ED nurse/999 call handler (e.g. HP01, NHS111).	NHS 111 (NHS24 in Scotland) is a non-emergency medical helpline free to use in the UK. GP is the accepted abbreviation for general practitioners – family doctors in the UK. Amb.tech is short for ambulance technician – they work with paramedics on ambulances but have less training. 999 is the telephone number for the UK's emergency service.
Stage 2	Parents	P for Parents, FG for focus group, FG number (e.g. FG1), M for Mother or F for Father followed by respondent number (e.g. P,FG2,M7). Parents who contributed by telephone are identified as P,FGT. Parents who contributed by email as P,FG2 (e.g. P,FGT,M1 or P,FG2,M2).	Three parent focus groups P,FG1 P,FG2 P,FG3
	Health professionals	Location of the focus group i.e. TH or DGH followed by HP,FG and the number of the focus group (e.g. TH,HP,FG2).	Individuals are identified by appending their service identified as for Stage 1.

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#### 245 **The illness: the Cause and beginning of the illness trajectory**

246 The beginning of all the children's journeys was the onset of illness. Of the 28 children whose  
247 parents shared illness trajectories with researchers, 10 children from Stage 1 were reported to have

248 a respiratory illness, one had tonsillitis and one had acute disseminated encephalomyelitis (ADEM)  
249 (see Table 5).

250 In Stage 2, 14 children were reported to have meningitis (five also had sepsis), one had urinary sepsis  
251 and one had bronchiolitis (see Table 6). The high number of children with meningitis in Stage 2  
252 reflects the success of recruitment through our charity partner, Meningitis Now.

253 The duration of the illness prior to admission to hospital varied from 12 hours to 12 days in Stage 1  
254 and from 12 hours to more than 2 weeks in stage 2 illustrating the individual and unpredictable  
255 trajectory of each child's illness.

256

257 **Table 5 Stage 1 Characteristics of each family and affected child**

258 TH Teaching hospital; DGH District general hospital; NP Nurse Practitioner; CAU Child Assessment Unit.

Stage 1 Case	Family members interviewed	Age band of affected child	Household composition	Pre-existing conditions (yes/no)	Diagnosis for this illness	Duration of this illness prior to admission	Services accessed pre-hospital and admitting unit
THP04	Mother	13-23 months	Two parents	Yes	?Bronchiolitis	3 + days	GP, CAU, Ambulance, ED, HDU
THP05	Father	Under 6 months	Two parents; 6 other adults and their 4 children	Unknown	RSV Bronchiolitis and Influenza A	Approx. 7 days	GP x3, EDx2, CAU, PICU
THP08	Mother and Father	2-4 year old	Two parents, grandparent and one young sibling.	Yes	?Chest infection	Approx. 6 days	GP, Ambulance, ED, PICU
THP10	Mother and Father	2-4 year old	Two parents and one younger sibling.	Yes	?Asthma attack and chest infection	1.5 days	NP at GP surgery, Ambulance, ED, PICU
THP12	Mother	2-4 year old	Two parents and two older siblings.	Yes	Asthma attack and chest infection	Approx. 12 hours	NP at GP surgery x2, ED, HDU
THP18	Mother, two other family carers	2-4 year old	Two parents, one younger and one older sibling.	No	<i>'Chest infection and later pneumonia, fluid around the lung and Strep A blood infection'</i>	2.5 days	NHS 111, Ambulance, ED, HDU/PICU
THP21	Mother and Father	2-4 year old	Two parents and two older siblings.	Unknown	ADEM - Acute disseminated encephalomyelitis	6 days	GP x2, ED x2, Walk-in Centre, ED, HDU/PICU
THP22	Mother and Father	2-4 year old	Two parents	Yes	Tonsillitis with obstruction	7 days	Walk-in Centre, locum GP, NHS 111, Ambulance, ED, PICU
THP27	Mother and one other family carer	6-12 months	Two parents and one older sibling.	Yes	Bronchiolitis (recurrence) with obstruction	10 days	Ambulance, ED, PICU
DGHP01	Mother and Father	13-23 months	Two parents.	No	Collapsed lung and sepsis	12 days	GP x3, NHS 111, ED, HDU
DGHP02	Mother and Father	6-12 months	Two parents and one older sibling.	No	Collapsed lung secondary to ?chest infection/ pneumonia	Approx. 8 days	GP x2, NHS 111, Ambulance, ED, HDU
DGHP03	Mother and Father	2-4 year old	Two parents.	No	Pneumonia	7 days	GP, NHS 111, Ambulance, 999, ED, HDU/PICU

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**Table 6 Stage 2 Characteristics of each family and affected child**

P,FG1 = Parent Focus group 1, August 2019; P,FG2 = Parent Focus group 2, October 2019; P,FG3 = Parent Focus group 3, , October 2019; P,FGT = Parent Focus group alternative telephone interview: October 2019; P,FGE = Parent focus group alternative email interview: October 2019; M = Mother F = Father followed by the number of the participant e.g. M1

Stage 2 Case	Family members interviewed	Age band of affected child	Household composition	Pre-existing conditions (yes/no)	Diagnosis for this illness	Sequelae of the illness	Duration of this illness prior to admission	Services accessed pre-hospital and admitting unit
P,FG1, M1	Mother	6-12 months	Two parents and two children.	Yes	Bronchiolitis	Unknown	Unknown	ED, HDU
P,FG1, M2	Mother	6-12 months	One parent and four children.	No	Meningitis and sepsis	Right below elbow amputee. Acquired brain injury. Stomach damage causing food sensitivities. Growth plate damage	4 days	NHS111, Ambulance, ED, Ward
P,FG2, M1	Mother	2-4 year old	Two parents and six children.	Unknown	Meningitis	No bone growth in both legs due to sepsis. Now having treatment (lengthening and correcting the shape of the legs)	3 days	GP, 999, ambulance, 'Hospital'
P,FG2, M2	Mother	6-12 months	Two parents and three children.	Unknown	Meningococcal septicaemia	Unknown	24 hours	GP, ED, PICU
P,FG2, M3&F4	Mother and Father	Under 6 months	Two parents and two children.	Unknown	Late onset group B streptococcus meningitis	Child died	24 hours	GP, 999, ED, 'Hospital'
P,FG2, M5&F6	Mother and Father	2-4 year old	Two parents and two children.	Unknown	Meningitis B	Child died	< 24 hours	999, ED, PICU
P,FG2, M7	Mother	2-4 year old	Two parents and one child.	Unknown	Meningitis	Child died	3 days	ED, 'Hospital'
P,FG3, M1	Mother	2-4 year old	Two parents and two children.	Unknown	Meningococcal disease	Unknown	24 hours	GP, NHS111, Ambulance, ED, PICU
P,FG3, M2	Mother	6-12 months		Yes	Pneumococcal meningitis	Child died	2 weeks +	GPx4, ED, Adult HDU
P,FG3, M3	Mother	6-12 months	Two parents and two children.	Unknown	Pneumococcal meningitis	Unknown	2 weeks +	Walk-in centre, GP, ED, 'Hospital'
P,FGT, M1	Mother	13-23 months		Unknown	Bacterial meningitis and septicaemia	Unknown	2 days	OOHS GP, EDx2, 'Hospital'
P,FGT, M2	Mother	Under 6 months	Two parents and two children.	Unknown	Viral meningitis	Unknown	12 hours	NHS24, OOHS Nurse, Ambulance, ED, 'Hospital'
P,FGT, M3	Mother	Under 6 months	Two parents and one child.	Unknown	Meningitis	Unknown	12 hours	GP, ED, 'Hospital'
P,FGT, M4	Mother	Under 6 months	Three adults and one child	Unknown	Meningitis and sepsis	Unknown	<24 hours	NHS111, Urgent Care Centre, 'Hospital'
P,FGE, M1	Mother	Under 6 months	Two adults and four children.	Unknown	Urinary sepsis	Unknown	6 days	HV, NHS24 x2, OOHS GP, GP, ED, 'Hospital'
P,FGE, M2	Mother	Under 6 months	Two adults and three children.	Unknown	Meningitis and septicaemia	Growth plates affected result in leg length discrepancy	<24 hours	GP, GP OOHS, Cottage Hospital, Ambulance, PICU

N.B. 'Hospital' is given as the admitting unit where no information was provided about the unit to which the child was admitted.

## Navigating uncertain illness trajectories

### Defining the illness and its severity during the illness trajectory

Throughout the illness trajectory, parents had to make sense of the illness and its severity. Parents' ability to define the illness and judge its seriousness was affected by tiredness, distractions of family life, past experience, knowledge of symptoms/illness and not wanting it to be serious as the *'thought of it being something more is unbearable'* (P,FG2,M5). In the later stages of the trajectory towards hospital admission, parents perceived that the illness had progressed from minor to very obviously real and serious, often reported in this study as recognising *significant* differences from normal or that something was obviously *'not right..... he didn't look right* (DGH,P01,M); *'she's not right'* (P,FG2,M3). Before this point lay uncertainty about the legitimacy of seeking help; it is in this uncertain part of the illness trajectory that there are opportunities for parents to access earlier treatment. For some children whose illness progresses rapidly this window of time is very short.

Some symptoms of serious illness were not recognised by parents and, in a few instances, by health professionals (Box 2). The significance of wording and phrases used by parents to describe what was worrying them about their unwell child, such as *'not quite herself'* (P,FG2,M3) and *'not there behind the eyes'* (P,FG2,M7), were reported by some parents to be missed by HPs. The lack of recognition of these phrases illustrates the difficulties parents had in communicating their concerns about their child's illness in terms of symptoms that were recognised by HPs. For example, one mother explained:

*"That's where I struggle I think, to be able to explain why I know he's not right, but I get that a lot. I think I seem to just - it's just in me and I can't explain it. .... The amount of times I've said to him [Father], 'He's just not right, something's not right but I don't know what it is'"* (DGH,P01,M).

## Box 2 Missed symptoms of serious illness

Symptoms not recognised by parents	Symptoms not recognised by health professionals
<ul style="list-style-type: none"> <li>☐ 'Bruising', 'love bite', purple mark</li> <li>☐ Temp over 38°C in young baby</li> <li>☐ Lack of urine</li> <li>☐ Grunting</li> <li>☐ Head/back pain</li> <li>☐ Mottled skin</li> <li>☐ Sucking in under the ribs</li> <li>☐ Fast breathing</li> <li>☐ Funny cry</li> <li>☐ Staring</li> <li>☐ Stiffness</li> <li>☐ Non-response to paracetamol</li> </ul>	<ul style="list-style-type: none"> <li>☐ Purple mark (NHS 24 call handler)</li> <li>☐ Temp over 38°C in young baby (Out-of-hours service (OOHS GP))</li> <li>☐ Lack of urine (OOHS GP)</li> <li>☐ Grunting (ED doctor)</li> </ul>

## Parent help seeking during the illness trajectory

Parents made between one and six contacts with health services during their child's illness trajectory (see Tables 7-10). Use of the out of hours service (OOHS) was rarely reported. Various factors were reported by parents to affect children's trajectories: access to GP appointments – *"it's quite hard to get an appointment"* (DGH,P02,F), transport – *"We're stuck, especially with no car"* (TH,P10,F) and proximity to services – *"it is not far. That's why I chose it [Urgent Care Centre]"* (TH,P21,F). Psychosocial factors affecting parents' decision making about seeking help for their child are explored in Influencing Variables below.

### 303 **Table 7 Stage1 Illness trajectories**

304 TH Teaching hospital, DGH District general hospital, CAU Child Assessment Unit, NP Nurse Practitioner

Family identifier	Age band of child	Duration of this illness pre-admission	Diagnosis for this illness	Illness trajectory
THP04	13-23 months	3 + days	?Bronchiolitis	Struggling with her breathing, rash as well, to GP Wednesday, sent to CAU, in CAU for 6 hours, doctors debated keeping her in, discharged home with leaflet 'and told to look out for any recession', Friday morning vomited after breakfast, struggling to breathe, called ambulance, admitted to HDU
THP05	Under 6 months	Approx. 7 days	RSV Bronchiolitis and Influenza A	Coughing for a week, choking during coughing bouts, visited GP three times, cough worsening and going blue for 5 days, then ED, no coughing during consultation so discharged home, ED again, coughing episode witnesses so sent to CAU, admitted to PICU (no timeframe information).
THP08*	2-4 year old	Approx. 6 days	?Chest infection	Friday completed course of antibiotics, Mother away from home post surgery so cared for by Father (first time on his own), well until Sunday morning, Father detected high temp. gave Calprofen, called Mother, Mother visited Sunday evening, holds him, he is floppy, going grey around eyes and mouth, called ambulance Sunday evening, admitted to PICU.
THP10	2-4 year old	1.5 days	?Asthma attack and chest infection	Monday first ill, coughing and wheezing throughout the night, given inhalers, Mother didn't want to wake Father so waited for surgery to open next day, Tuesday saw GP NP who gave nebuliser, called ambulance, admitted to PICU.
THP12	2-4 year old	Approx. 12 hours	Asthma attack and chest infection	Thursday morning high temp and slight wheeze, saw GP NP who advised 'give him his pump', more wheezy by midday so took him back to see NP early afternoon, told to carry on as before, by 5pm 'gasping' and pushing very hard to breathe whilst sleeping, waited for Father to come back from work, then to pack bags including food for Mother as it was Ramadan, picked up other children from after school club, taken to ED that evening by car, admitted to HDU
THP18	2-4 year old	2.5 days	Chest infection and later pneumonia, fluid around the lung and Strep A blood infection	Family had all had 'it' in the preceding two weeks. Thursday first ill with temp, responsive to paracetamol, vomited in bed that evening, Friday slept on and off 'really, really hot', cared for by grandmother so Mother could Christmas shop, no bounce back on paracetamol, had wet herself when she woke, Grandmother advised seeking GP, Mother said she had but didn't, Father went to work Christmas party and stayed at his parents', Saturday morning lips 'all white', thought it was dehydration, called NHS111, ambulance sent, ED, ED consultant 'on the fence' about her until chest X-ray results, admitted to HDU/PICU
THP21	2-4 year old	6 days	ADEM - Acute disseminated encephalomyeli	Language difficulties. Sunday first ill with D&V and temp a bit high, Monday GP, Tuesday GP, told it was flu', Wednesday ED with Father 6-7 hours told

			tis	it was viral and sent home, getting worse and nose bleed, Thursday ED with teenage daughter to translate, taken less seriously than when Father took her so sent home, Friday not drinking or eating and floppy so evening to walk-in centre as it was close to them, took blood, told 'low blood count' sent to hospital 'Just go now', admitted to HDU/PICU.
THP22*	2-4 year old	7 days	Tonsillitis with obstruction	Sunday cough, temperature responsive to paracetamol, walk-in centre red throat and given antibiotics, Wednesday no improvement > locum GP changed antibiotics, seemed to get a bit better until Saturday evening when she woke from sleep blue around lips and eyes, really struggling to breathe, called NHS111 who sent ambulance, resuscitated in ED, PICU
THP27*	6-12 month old	10 days	Bronchiolitis (recurrence) with obstruction	Previous admissions with bronchiolitis, worse for him because he had tracheobronchomalacia. Worried about being judged by HCPs as paranoid parent. Friday first ill for this episode of illness. Much worse Wednesday and Thursday. Saturday seemed better. Late Sunday night/Monday morning Mother went to his room to find him really distressed, he gasped and stopped breathing. 1am Monday morning resuscitated at home by Mother, called ambulance, ED, PICU.
DGHP01"	13-23 months	12 days	Collapsed lung and sepsis	Previous visits to ED with chickenpox, infection and high temp after immunisations. GP for antibiotics twice in preceding weeks, then Tuesday/Wednesday picked up a cold from playgroup, Wednesday following week GP tonsillitis and given antibiotics, felt reassured, Mother sent Father videos of him during the day, breathing quite hard, temperature hard to manage, relayed calling due to prior criticism from nurse, Friday night not eating or drinking or weeing so NHS 111 wanting OOHS GP, NHS 111 wanted to send ambulance but parents chose to take him in their care to ED, HDU
DGHP02	6-12 months	Approx. 8 days	Partially collapsed lung secondary to ?chest infection/pneumonia	A bit wheeze all week, then Monday a bit wheezy at nursery, Monday evening GP nothing to worry about, come back if it gets worse, Tuesday night woke from sleep really struggling, asked grandmother advised to seek help, sucking in at the ribs so called NHS 111 who sent ambulance, given nebuliser, taken to ED, HDU
DGHP03	2-4 year old	7 days	Pneumonia	Monday sent home from nursery with temp., Tuesday GP to satisfy nursery, lots of people ill, reassured by having seen the GP, Saturday coughing at night, NHS 111 about midnight, Ambulance – sent away, Sunday phoned for appointment, GP appointment 2.30pm given antibiotics, evening not keeping fluids down, unable to stop coughing, called 999, advised to go to ED in their own car for speed, HDU/PICU

305 \*Lots of prior hospital admissions. " Lots of prior visits to ED.

# Table 8 Stage 2 Illness trajectories

P,FG2 = Parent Focus group 1, August 2019; P,FG2 = Parent Focus group 2, October 2019; P,FG3 = Parent Focus group 3, October 2019; P,FGT = Parent Focus group alternative telephone interview, October 2019; P,FGF = Parent focus group alternative email interview, October 2019; M = Mother F = Father followed by the number of the participant e.g. M1

Stage 2 Case	Age band of child	Duration of this illness pre-admission	Diagnosis for this illness	Illness trajectory
P,FG1,M1	6-12 months	Not known	Bronchiolitis	Previous experience of NHS 111 sending ambulance when it was not warranted put them off calling them and delayed help seeking. Mother's Day, Mother out with friends, Father phoned to say breathing really bad, instructed Father to give inhaler, Mother came home and saw she was gasping for breath > to ED in their car > Adult resusc > Paediatric HDU
P,FG1,M2	6-12 months	4 days	Meningitis and sepsis	Bit of a temp for 4 days, gradually increasing > floppy, 'ash grey', tensing, vomiting, high temp. over 41 on paracetamol Friday night > Phoned NHS 111 (didn't want to call 999 unnecessarily) > ambulance to ED 8pm at a weekend > ward at 1am for 27 hours > discharged but Mother refused to leave, Mother took photos to track visible changes in him and made notes > deteriorated, hand went black within 45 minutes > HDU > transferred to teaching hospital, legs black > right arm amputated, stroke.
P,FG2,M1	2-4 year old	3 days	Meningitis	Ill for 2 days in December, woke at midnight with high temp. unresponsive to paracetamol > ibuprofen, shaking > 6am whimpering, mottled skin, sunken eyes > watched TV, sore head > paracetamol worked > ate breakfast, napped, 'love bite' on his arm > glass test > checked symptoms on google > phoned GP who said 'you decide' whether to call 999 > called 999 > collapsed > phone grandad while waiting > fast response car, semi-conscious, given ABs > hospital.
P,FG2,M2	6-12 months	24 hours	Meningococcal septicaemia	Woke crying, high temp., came down in response to paracetamol, diarrhoea, slept with Mother, woke in the morning with funny breathing, very still > rang GP, no urgent appointments > took child to GP demanding to be seen > GP told them to go straight to ED > PICU
P,FG2, M3&F4	Under 6 months	24 hours	Late onset group B streptococcus meningitis	Had a cold > GP as not 'quite herself', Mother worked there and GP trusted her judgement and didn't examine her > early hours of the morning Mother 'jolted awake' as she hadn't woken for a feed, floppy > rang 999 > hospital > died
P,FG2, M5&F6	2-4 year old	< 24 hours	Meningitis B	Came home from nursery saying back hurts (there were lots of coughs and colds about), went to bed as normal, sick in the night, up with her 5.30am, 'bruise' on her eyebrow, vomiting, very quiet, bath, spot on leg, just lying there, 'knew something bad was wrong' > 999 > ED leg purple > PICU > died 13 days later
P,FG2,M7	2-4 year old	3 days	Meningitis	Ill for 2 days, had a nap on the sofa, tried to wake him, eyes not right 'It was like he wasn't there behind his eyes' > neighbour for help > hospital, unconscious > resusc > died within a day.
P,FG3,M1	2-4 year	24 hours	Meningococcal	Nursery Mon am, pm sofa day, then vomiting, rang GP

	old		disease	– no appointments, high temp. in the evening, shaky and hallucinating, phoned 111 as husband thought need an ambulance, NHS 111 sent ambulance > ED, purple blotching on chest, rapidly spreading > ICU > transferred to London hospital
P,FG3,M2	6-12 months	2 weeks +	Pneumococcal meningitis	Ear infection, 3 lots of antibiotics, back to GP Friday 4pm, saw different doctor > ED Saturday as she was staring and stiff > Adult HDU > transferred to London hospital > brain dead Sunday > <b>died</b> .
P,FG3,M3	6-12 months	2 weeks +	Pneumococcal meningitis	Ill on and off for 2 weeks > walk-in centre > sent home, suddenly very, very sick at night, spine and head hurt > saw GP 9am, told ' <i>nothing that sinister</i> ' but Mother asked if he should go to ED, GP response ' <i>I guess</i> ' > ED, deteriorated within an hour > in hospital for 10 days.
P,FGT,M1	13-23 months	2 days	Bacterial meningitis and septicaemia	Weekend. Woke in the night on Friday, vomited, high temp.. A bit unwell Saturday had a couple of spots > glass test, ' <i>kind of disappeared</i> ', temp 39.7 > rang OOHS GP > saw GP almost immediately, temp over 40 > referred to hospital > discharged, told ' <i>it's probably just chickenpox</i> ', given advice sheet on caring for a child with a fever. Perked up, ate and drank, played with her sister. Vomited Saturday night, high temp.. Sunday morning floppy and not very responsive. Waited until Sunday early evening before taking her back to the hospital. Had a couple more spots. Admitted. Recorded diary of events during hospital stay.
P,FGT,M2	Under 6 months	12 hours	Viral meningitis	Bank holiday Monday. Day out on the beach. Irritable, thought it was the hot weather. On return home, sniffly and high temp. > checked NHS website > phone NHS 24 > OOHS Nurse Practitioner noticed distressed on handling and mottled legs > Ambulance > admitted. Mother had no idea that it was serious.
P,FGT,M3	Under 6 months	12 hours	Meningitis	Grizzly and crying unusual for him one morning. Temp 38 > given paracetamol > temp continued to rise to 40, not feeding > asked grandmother, asked online groups, googled > rang GP > advised to ring 999 > grandmother drove them instead. Had a ' <i>small rash</i> ', blanched with glass test. Didn't want to waste NHS time in an overburdened system.
P,FGT,M4	Under 6 months	<24 hours	Meningitis and sepsis	Had gastroenteritis 10 days before. Wednesday poorly, crying on and off all day, overnight unsettled, feeding very little, large vomit after a feed, temp 39.2, grey/yellow colour > NHS 111 > OOHS appointment > phoned by Urgent care centre at hospital to come straight there instead, temp 39.9 & vomited > admitted.
P,FGE,M1	Under 6 months	6 days	Urinary sepsis	Initially snuffly on Wednesday/Thursday, Friday saw HV who noted she was unwell but not concerned, 11pm woke with temperature > Called NHS 24, ' <i>just a cold</i> ' > googled, read NICE guidelines, Saturday not feeding, temp. over 39, lack of urine > NHS 24 > OOHS GP, not concerned, Sunday temp spikes, fretful not feeding, Sunday night breathing fast, funny cry, Monday pm floppy and lethargic ' <i>she looks like she is dead</i> ', almost grey, temp 41 > GP > hospital. NB Delayed help seeking after Saturday consultation

				due to criticism, false reassurance 'It's just a cold'.
P,FGE,M2	Under 6 months	<24 hours	Meningitis and septicaemia	Just after Christmas, snow. High temperature > phoned GP, advised to give paracetamol and ibuprofen, monitor for new symptoms/worsening, if yes, ring surgery. Middle of the night, strange whinge, diarrhoea and a purple mark on his belly>checked for symptoms of meningitis online >rang GP OOHS > cottage hospital in the snow, OA lips turning blue, pale, heavy breathing, given Abs, oxygen >called ambulance >hospital >retrieval unit>children's hospital PICU. NB 'Unable to word it out (meningitis) to my husband or anyone on the phone'

311

### 312 Table 9 Stage 1 Children's help seeking on their illness trajectory to hospital admission

313 Please note that these are not presented in the order in which parents made contact with these services.

314 THP = parent recruited in the Teaching Hospital; DGHP = parent recruited in the District General Hospital

Stage 1 Case	Duration of illness	Social network	Primary care	Urgent care / walk-in centre	NHS 111	OOHS	999/ Ambulance	A&E/CAU	Pre-admission contacts with health services
THP04	3 + days		●				●	● ●	4
THP05	Approx. 7 days	●	● ● ●					● ● ●	6
THP08	Approx. 6 days		●				●	●	3
THP10	1.5 days		●				●	●	3
THP12	Approx. 12 hours		● ●					●	3
THP18	2.5 days	●			●		●	●	3
THP21	6 days	● ●	● ● ●	●				● ● ●	6
THP22	7 days		●	●	●		●	●	5
THP27	10 days						●	●	2
	12 days		● ● ●		●			●	5
DGHP01									
DGHP02	Approx. 8 days	●	● ●		●		●	●	5
DGHP03	7 days		●		●		● ●	●	5

315

### 316 Table 10 Stage 2 Children's help seeking on their illness trajectory to hospital admission

317 Please note that these are not presented in the order in which parents made contact with these

318 services.

319 P,FG2 = Parent Focus group 1, August 2019; P,FG2 = Parent Focus group 2, October 2019; P,FG3 = Parent Focus

320 group 3, October 2019; P,FGT = Parent Focus group alternative telephone interview, October 2019; P,FGE =



321 Parent focus group alternative email interview, October 2019; M = Mother F = Father followed by the number  
322 of the participant e.g. M1

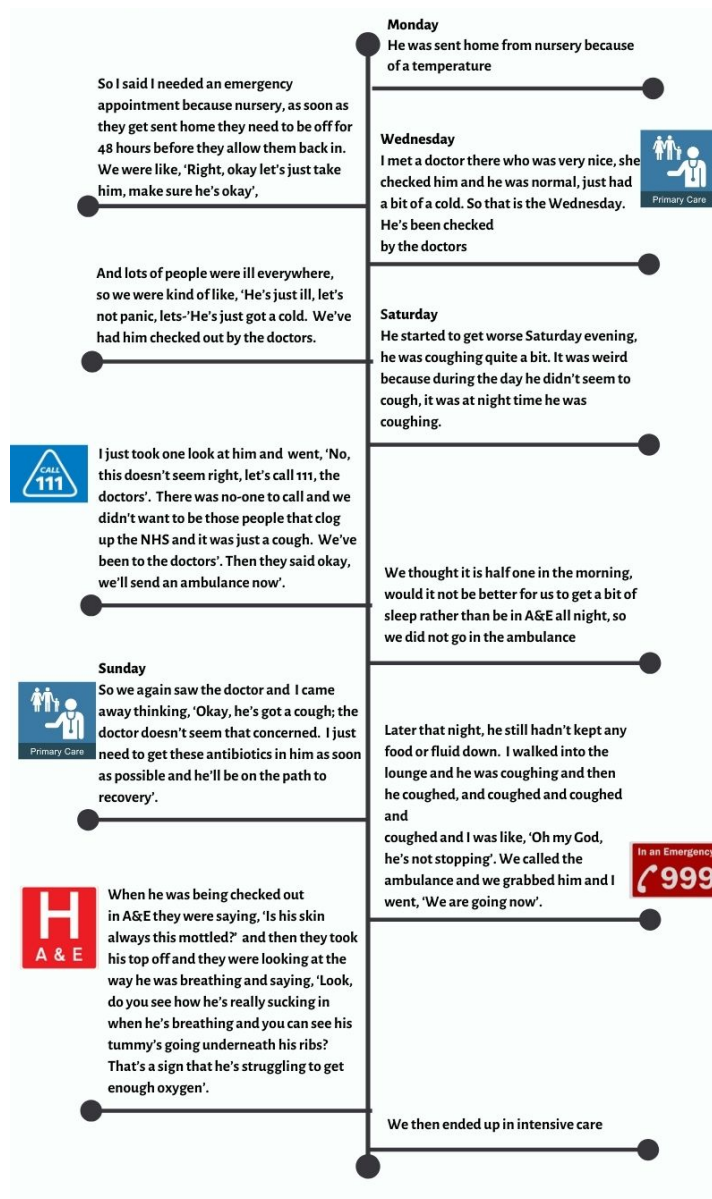
Stage 2 Case	Duration of illness	Social network	Primary care	Urgent care / walk-in centre	NHS 111/ NHS24	OOHS	999/ Ambulance	A&E/CAU	Pre-admission contacts with health services
P,FG1,M1	Not in the data	●						●	1
P,FG1,M2	4 days				●			●	3
P,FG2,M1	3 days		●				●	●	3
P,FG2,M2	24 hours		●					●	2
P,FG2,M3&F4	24 hours		●				●	●	3
P,FG2,M5&F6	< 24 hours						●	●	2
P,FG2,M7	3 days	●						●	1
P,FG3,M1	24 hours				●		●	●	3
P,FG3,M2	2 weeks +		●					●	2
P,FG3,M3	2 weeks +		●	●				●	3
P,FGT,M1	2 days					●		● ●	3
P,FGT,M2	12 hours				●	●	●	●	4
P,FGT,M3	12 hours	●	●					●	2
P,FGT,M4	<24 hours			●	●				2
P,FGE,M1	6 days		● ●		● ●	●		●	6
P,FGE,M2	<24 hours		●			●	●		3

323

324 The children's trajectories were often complex, particularly when the child was ill for longer before  
325 admission. Fig 4 presents an example of one child's trajectory showing the timeline and the number  
326 of health service contacts.

327 **Figure 4 One child's trajectory from onset of illness to district general hospital admission**

328 2-4 year old living with both parents, no sibling, pneumonia



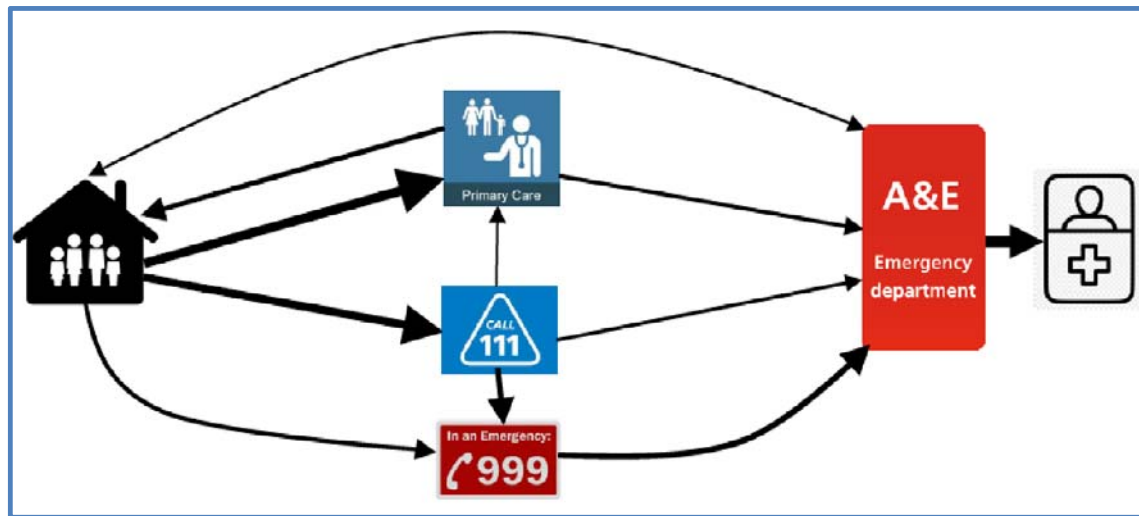
329 As in this child's case, children were likely to have been seen in primary care more than once and/or

330 to have used emergency care and been sent home, only to present again at a later stage in the

331 illness. Fig 5 shows the pathways of service use with thicker arrows for more common illness

332 trajectories.

**Figure 5 Pathways to hospital admission**



## The family and the health services: Context

The family is the immediate context and the starting point for a child's illness trajectory. Typically, families were busy and reported juggling multiple work and family agendas (See Tables 5 and 6 for characteristics of the families in the study). Parents' reports showed how the nature of family life could delay help seeking especially if a parent was on their own with their child/children. Delays encompassed, for example, waiting until the morning *"she was quite bad that night but I thought 'I'll take her in the morning'"* (TH,P10,M) and juggling other commitments *"I had to get the other kids to school"* (P,FG1,M2) or diverting to pick up another child from childcare *"We took him straight to the A&E, but half past six because my children were at evening classes so we picked them up on the way"* (TH,P12). Few parents reported seeking help/advice from people in their family and wider social network instead managing the illness within the immediate family unit.

Health services were the other main component offering context for these children's illness trajectories. Urgent and primary care services differed between geographical areas, providing the landscape of services within which parents were making decisions about seeking help. The TH area had six urgent care centres and one children's ED while the DGH area had one urgent care centre

and a children's area in a general ED. Urgent Care Centres varied, some were Walk-In centres, whilst others require appointments to be booked through NHS111. These variable patterns of health service provision were reflected in the patterns of health service use identified in our analysis of HES data, with lower rates of ED attendance in areas provided with more urgent care centres. GPs, in the focus groups, reported that practices in primary care have variable telephone triage and appointment systems and, if the system is time ordered such as a sit and wait system, this may generate significant delay before a child is seen and assessed.

This complexity of services led to confusion and a lack of consistent advice. Both parents and HPs reported that they do not always know where to seek help for the level of illness. One HP (who was also a parent) discussed the complexity of services:

*"I had a leaflet through. It was about 10 pages from the Local Authority and it was "Choose well" and it was an 8 colour-coded scale and some examples of the different things you could do, from going to see a pharmacist to calling 999 and I am thinking, "I'm a [health professional] consultant and I'm confused!" (TH,HP,FG1).*

Typically, HPs reported that they thought this complexity was a result of risk averse health cultures and algorithms that refer large numbers of children to hospital.

## **Social expectations and social hierarchies: the antecedents.**

Two broad categories of antecedents were identified: social expectations and social hierarchies.

### **Social expectations**

Parents report moral responsibilities to protect their child *and* use services only when necessary, by doing the '*right thing*' (P,FG2,M3) for their child whilst also not misusing or overusing services "*I didn't want to go to hospital and just trouble them for no reason*" (TH,P12). Of course, these twin responsibilities are sometimes in conflict and can cause dilemmas when parents are unsure about

the severity of illness of their child and consequently, whether it warrants health service use, for example:

*“So I still kick myself and say I should have just called an ambulance and took her there and then. I feel so silly that I waited ‘til 4pm for the GP appointment”* (P,FG3,M2).

This mother’s decision making appears to have been shaped by her perception of the social rules for service use as she was not aware that her child was seriously ill, illustrating the dilemma parents face of needing to balance their child’s needs with conforming to social rules and expectations.

HPs differed from parents as they reported a moral responsibility to accurately assess and treat the child whilst also controlling demand for services. One GP talked about the often higher demand from first time parents and his strategy to reduce these parents’ demand in the future explaining *“that’s how you educate them, knowing that if you give them 2 or 3 consultations this time, you are likely to reduce the consultations in the long run”* (TH,HP,FG1).

## Social hierarchies

Parents’ stories illustrated their perceived powerlessness when trying to seek help for their child, illustrating a social hierarchy within which health professionals hold the power. This powerlessness was seen in parents’ distress when they were unable to secure help for their child, for example:

*“I wasn’t listened to, I wasn’t listened to at all. It was not my son, that was not my son’s typical behaviour; that was not what he normally looked like. It just wasn’t him, and there was something wrong. It didn’t matter how much I tried to convey that”* (P,FG2,M2)

Power was evident in HPs’ accounts of managing demand and in gatekeeper roles. Professionals hold privileged knowledge, on which parents rely, even in this era of the internet, while parents reported that their expert knowledge of their child was ignored; one health professional also noted that parental expertise could be ignored as explained below in Consequences.

## InfluenCing variables or Contingencies

Degree of uncertainty, knowledge and experience, temporal factors, number of children presenting to services and relational continuity were identified as influencing variables on the child's illness trajectory from parents' decision making about seeking help to interactions between parents and health professionals.

## Uncertainty

Several forms of uncertainty were reported by parents: diagnostic, symptom, trajectory and symbolic. Diagnostic uncertainty, not *being "sure what was wrong with her all the way, to be fair"* (TH,P10,F), was frequently reported by parents and sometimes by HPs. Parents specifically reported symptom uncertainty, not knowing what symptoms to expect or which ones indicate serious illness.

Trajectory uncertainty, not knowing the course of the illness, was implicit in parents and professionals' accounts. One parent's account illustrated both HPs' uncertainty and, later in the same interview, her own uncertainty about the likely trajectory of her daughter's illness:

*"..after about a third opinion [from doctors in ED] they decided that they weren't worried and that it was viral and that she could come home but keep an eye on her"* (TH,P04,M).

And later in the same interview:

*"Because the doctor had already said she could get worse before she gets better but just watch for her breathing. And she did get worse, a lot worse before getting any better, and then worse again so it's knowing what's that cut-off before you think, 'Is this the turning point? Is this the peak of the illness where she's going to be better tomorrow?"* (TH,P04,M).

Symbolic uncertainty (how behaviour will be viewed by others) was most often represented in parents' accounts of worry about re-consulting such as *"I wanted a second opinion. Because I don't want to do anything that's going to cause --- when I go to hospital and it's nothing"* (TH,P12, M).

## Knowledge and experience

Parents' knowledge or lack of knowledge of their child's illness, experience of illness and of interactions with health services, including learning about symptoms, *"we knew about the sucking in at the ribs from times we had been [to GP]"* (DGH,P02), influenced their decision making. HPs also reported that parents' experience of different health services abroad influenced where parents sought help. For example one HP stated: *"a lot of Polish people tend to go to A&E instead of going to the GP"* (TH,HP,FG2), as this is how they expect services to work from their knowledge of services in their country of origin.

HPs' knowledge influenced their ability to identify signs of SII. Where HPs had little child specific education, they relied on personal, often parenting, experience, such as *"My crew mate that I work with full-time has got 4 children, so I just let her deal with it"* (TH,HP,FG1) or algorithms which did not always address the specific situation, *"we don't really have pathways for babies"* (HP01-NHS111).

## Temporal factors

Time of day/week, family life and social events influenced where and when parents sought help. Services are structured differently overnight and at the weekend, for example, some parents waited until their doctor's surgery opened in the morning, and at weekends some were limited to phoning NHS111/NHS24 or the 999 ambulance service. One father explained:

*"Well, we decided that we'd try and get him to the out-of-hours GP but you can't access - we wanted to take him to the Urgent Care Centre at X but - we'd looked on the internet and you can't access that until you've spoken to 111"* (DGH,P01,F).

Patterns of family life were another influence, for example, if one parent was at work or a social event the other waited for their return before seeking help:

445 *"I didn't want to go to hospital and just trouble them for no reason. So I wanted a second opinion so*  
 446 *when my husband came back from work, my son was sleeping and I asked him, 'Look at our son and*  
 447 *what do you think?' He goes, 'I think we should take him straight to hospital'" (TH,P12,M).*

448 Parents' working patterns were perceived by HPs to be responsible for predictable peaks in  
 449 presentations to emergency care.

## 450 **Number of children presenting to services**

451 All HP participants talked about the difficulties of the number of children presenting to services  
 452 (rarely framed as too few staff to meet the needs of the children). This high demand for services was  
 453 described as creating "*noise*" (TH,HP,FG1) making it hard to identify the few seriously ill children  
 454 amongst the increasingly large number of attendees. One ED doctor summed up the situation "*we*  
 455 *have made the haystack bigger. There is still only one needle but the haystack is enormous"*  
 456 (TH,HP,FG1). Another effect of this 'noise' was that it created an expected pattern that every child  
 457 has a minor illness and is "*just another one of them*" (HP09 Amb.tech) and unless symptoms  
 458 obviously indicate more serious illness professionals are likely to 'recognise' the pattern as one of  
 459 minor illness.

## 460 **Relational continuity**

461 Continuity of relationship between the family and their GP or primary care Nurse Practitioner was  
 462 reported to help HPs recognise differences from the child's normal:

463 *"I took her down to our local GP and they agreed with me, because they've seen E a few times, that*  
 464 *she wasn't herself"* (TH,P04).

465 However, limited continuity meant that HPs had no pictorial memory of the child or of their usual  
 466 health status. Consequently, professionals were reliant on access to records of past consultations  
 467 and the parent's accounts of their child's illness. GPs reported that managing 'demand' has reduced



relational continuity noting that relational continuity *“is important but it is very difficult, especially working GPs now”* (DGH,HPFG,GP). This was justified with reference to the value of *“fresh eyes on the problem”* (DGH,HPFG,GP). This GP identified a possible benefit to not having seen the child before.

## Consequences

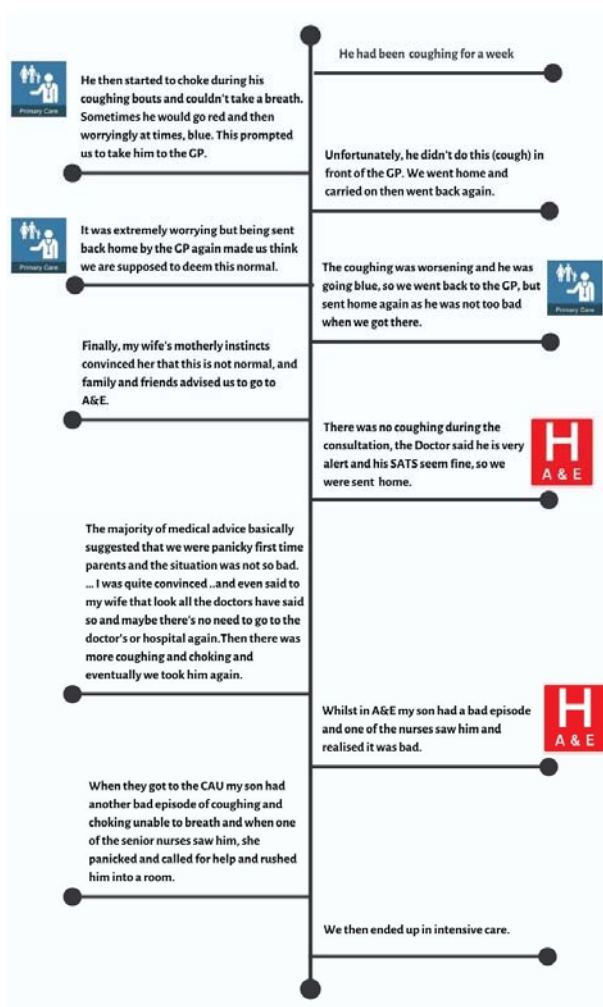
### Powerlessness and loss of control

Parents experience a loss of control of their child’s health before they seek help: *“I’m the Mum, I should be able to make my child better, but I couldn’t”* (P,FG3,M1) and sometimes during help seeking when it was *“just nerve wracking because I felt like I could see a decline in my son and I didn’t want to phone [NHS 111] back because I didn’t want to tie up the phone line.”* (P,FG1,M2) in case NHS 111 or a doctor called back while she was on phone. Unequal power between parents and HPs increased parents’ powerlessness and their struggle to be heard. One of the five ED doctors in the study explained that *“I don’t think you should necessarily be influenced that much by what they [parents] say”* (TH,HP,FG2-ED Doctor). Some parents thought their difficulties in being heard were related to being labelled as *“panicky first-time parents”* (DGH,P01), or to difficulties describing symptoms.

Parents reported having to provide incontrovertible evidence of their child’s symptoms, in order to feel ‘heard’ by professionals. One parent explained *“my son had another bad episode of coughing and choking unable to breath and when one of the senior nurses saw him, she panicked and called for help and rushed him into a room.....”* (TH,P05), before their concerns were taken seriously, after which *“they then watched him closely”* (TH,P05). An example of a trajectory, illustrating these difficulties, is presented in Fig 6.

**Figure 6 One child's trajectory from onset of illness to teaching hospital admission**

**Under 6 months in a family with four other children, RSV bronchiolitis and influenza A**



Another family, seeking help by phone, resorted to holding the phone to their child so that the call handler could hear the sounds the parents were trying to describe, noting, “it’s like, ‘is she making a noise?’ ‘Yes, she’s doing this’ [I] Put them on speaker” (TH,P22). One mother took photographs of her son while they were waiting in the emergency department so that she could show how he had changed during the time they were waiting in the department:

“I’d be taking pictures because I kept noticing new things. And I said to them, ‘Look, this is what he looked like at 8 o’clock when we came in, and this is him now.’ And they were like - yes okay, he’s

501 *looking a little bit peaky; we'll keep you in. Perhaps he just needs some fluids. So that's when they'd*  
 502 *taken us to the ward, but that had been a fight already" (P,FG1,M2) .*

503 Desperation was evident in the accounts of parents whose concerns were not addressed:

504 *"There were no paediatric staff around so the first nurse we saw said, 'Why have you come here*  
 505 *today? What's wrong?' I said, 'Just look at her'. I wanted to scream, 'Look at her'. So she was*  
 506 *brought straight in to the examination. It was a Junior Doctor and he was looking at her and saying,*  
 507 *'So what's the problem?' We were like, 'Well she's lethargic, she hasn't eaten and drunk, this is her*  
 508 *third lot of antibiotics, she's not making any vocal noises, she's staring'. My husband said, 'Maybe*  
 509 *she's just tired', and I looked at him. The Doctor was like, 'Yes, maybe she's just a bit tired, maybe she*  
 510 *just needs rest'. At this stage I was ready to scream the place down" (P,FG3,M2).*

## 511 **Perceived criticism and delayed help seeking**

512 Parents who had experienced criticism for using services early in their child's illness, delayed seeking  
 513 help to avoid further criticism from those professionals perceived to be in positions of power. This  
 514 parental dyad (DGH,P01) shared their experiences of criticism and how it has affected later decision  
 515 making:

516 *Father: I think we were trying to avoid going to A&E because we'd had a negative experience before*  
 517 *where we'd taken him to hospital. .... you took him down to ED but the nurse said basically there's*  
 518 *nothing wrong with him, you've wasted our time and -*

519 *Mother: She [the ED Nurse] said that A&E is emergency only and it's not just to be used really. And it*  
 520 *just made me feel really rubbish and I just - I didn't want to say, I didn't - maybe I should have but I*  
 521 *didn't say, 'I'm a nurse and I wouldn't have brought him in if I wasn't concerned'.*

522 *But she was very dismissive. And even as a nurse myself it did make me feel like this. I felt really*  
 523 *stupid almost and she was just really dismissive.... it put me off.*

Experiences of criticism appeared to reduce parents' self-efficacy with parents reporting that it made them doubt their ability to assess their child as they *"don't know what's right any more"* (THP27) adding to uncertainty and loss of control. Parents' reluctance to re-consult was also influenced by HP's reassurance that nothing was seriously wrong with their child, for example, *"being sent back home by the GP made us think we are supposed to deem this normal"* (TH,P05).

A sense of courage was evident in accounts from parents who persisted in raising concerns underpinned by their fear for their child's life, often in the face of criticism and disbelief. Sometimes it took a deterioration in their child's condition to legitimise their concerns. Persisting in this way was reported to be an added stressor on top of their worries about their child.

*"You feel like you are gearing up for battle every time. If you've got an issue with something it's like the gloves have to come out and you have to be like, 'I'm going to fight', and that's the only way that you seem to get anywhere with anything"* (P,FG1,M2).

Courageousness was also present in HPs' accounts when they acted as advocates for a child in the face of criticism from colleagues for example ambulance staff not wanting to be criticised for taking non-urgent cases to hospital. This fear of criticism clearly illustrates the power of social hierarchies. In our data these social hierarchies affected not only the parents but also HPs in a lower hierarchical position.

## **'Layers of risk' and risk management**

In primary care, GPs referred to *"layers of risk"* (TH,HP,FG1,GP) inherent within each step of the primary care system. These steps encompassed the time *"from the parent calling or not calling, or calling too late, to receptionists passing information immediately or too late or putting it down as a routine call to the clinician"* (TH,HP,FG1,GP) to the consultation itself. All these steps could contribute to delay in access to medical assessment. HPs felt that managing these layers of risk via

547 risk averse organisational systems (for example NHS111 algorithms) had increased the burden on  
548 services.

549 *“It’s well recognised that, for children, 111 is a flawed system. It was designed to be a system that*  
550 *was safe and it delivers on that, by definition of bringing everybody to a health care provider it’s*  
551 *safe”* (TH,HP,FG2,Amb.tech).

552 HPs reported managing the risks inherent in uncertain illness trajectories by providing safety-netting  
553 advice to families in the form of information concerning what to look out for and when to re-consult,  
554 sometimes in printed form but more often verbal advice. Parents sometimes referred to being given  
555 disease specific information but most often recalled safety netting advice as *“if she gets worse bring*  
556 *her back”* (P,FG2,M1), but questioning *“what is ‘worse’?”* (P,FG2,M3); this added to uncertainty and,  
557 despite the best intentions of safety netting practices, not reducing the risk of missing serious illness.

## 558 Discussion

559 We set out to retrospectively identify organizational and environmental factors and individual child,  
560 family and professional factors affecting timing of admission to hospital for children under 5 years of  
561 age with SII. Understanding factors in children’s journeys to hospital which contribute to avoidable  
562 deaths is now (in 2020/21) even more important given the constraints on families and health  
563 services during the Covid-19 pandemic. Using a modified grounded theory approach generated the  
564 emergent explanatory theory presented above. The core category ‘navigating uncertain illness  
565 trajectories’ is the psychosocial process, essential to Glaserian grounded theory (8, 10), to which all  
566 the other categories relate. Navigating is defined as ‘finding one’s way through, along, over or  
567 across something’ (15).

568 Pervading our findings were the social structures, social hierarchies and social expectations, which  
569 shaped an individuals’ behaviour. These social structures appear to have a more powerful impact on

570 children's illness trajectories from falling ill at home to being admitted to hospital for treatment than  
571 any individual characteristic. Children who were ill for longer before being hospitalised were likely to  
572 have more complex trajectories. Social hierarchies and social expectations are the social antecedents  
573 that pre-exist in society and consequently shape these uncertain illness trajectories.

574 Social hierarchies present a social structure within which people have more or less power depending  
575 on their perceived social value in a given setting (16). The power imbalance between professionals in  
576 different hierarchical positions is well known (17) as is the powerlessness of parents in the parent-  
577 health professional relationship (18). The unequal power created by these social hierarchies was  
578 evident in parents and HPs' accounts of their interactions in this, and prior, research in this area (19),  
579 making it difficult for parents to raise concerns about their child.

580 Social expectations are the written and unwritten rules of social life that we learn from our social  
581 interactions and that inform how we perceive we are expected to behave (20-22), consequently  
582 influencing parents' decision making about when to seek help. Social expectations are often  
583 considered to be the moral rules for everyday life. Acting outside of these moral rules requires  
584 courage as illustrated in parents' accounts of persisting in raising concerns, because perceived  
585 transgression may result in those actions being criticised (23). Such criticism was reported to delay  
586 help seeking to avoid further criticism from those in positions of power (24-30). Parents want to  
587 manage the impression they make on others as morally good parents and as good citizens who use  
588 services appropriately, reflecting prior research (13, 24, 26, 29-31).

589 Parents and HPs' moral frameworks differ (32), as seen in our findings where parents are trying to do  
590 the right thing for their child and use services in accordance with social expectations and HPs are  
591 focussed on accurately assessing and treating the child whilst also controlling demand for services.  
592 Balancing the child's needs with conforming to expectations concerning service use reflects earlier  
593 research (33). However, social rules are often unclear and mixed/conflicting messages occur,  
594 creating uncertainty for parents and sometimes for professionals.

595 Influencing factors identified in our findings include these uncertainties which led either to parents’  
 596 repeated help seeking or to delay in seeking help. Previous parental research identified all the forms  
 597 of uncertainty identified here (34-36). Uncertainty led HPs to provide safety netting advice, originally  
 598 conceived, as also reported here, as a way to manage the clinical risk associated with uncertainties  
 599 around the diagnosis or anticipated illness trajectory (37). However, this safety netting advice has  
 600 been found to be very variable in content and delivery (38). Parents reported that the mode of  
 601 delivery was usually verbal, although it is known that up to 80% of verbal information is not retained  
 602 (39). While some parents reported being given precise information about symptoms, such as  
 603 *“sucking in at the ribs”*, others reported simply being told to come back if *“it gets worse”* or *“if you*  
 604 *are worried”* – neither instruction was sufficiently detailed to enable parents to know when was  
 605 worse enough or how much more worried they needed to be (given that they were already worried  
 606 enough to seek help). Knowledge and experience influenced parents’ decision making as seen in  
 607 other research (13, 19, 33). Research has found that safety netting information needs to provide  
 608 information on how to assess the severity of symptoms for all the child’s symptoms, supported by  
 609 information on how to care for the child and in written or recorded format (28, 40, 41). Temporal  
 610 factors were also identified as influencing children’s trajectories, previously described as socio-  
 611 temporal factors (30) or timing-related factors (13), reflecting the interrelationships between time  
 612 and the social environment of family life, working patterns and variation in how services were  
 613 provided. The high demand for services reported was perceived to create an expected pattern that  
 614 every child has a minor illness, increasing the likelihood that HPs will ‘recognise’ the pattern as one  
 615 of minor illness. This is a form of recognition primed decision making (42) which has been described  
 616 in general practice as a rapid intuitive system (43).

617 Organisational and environmental factors were also identified, ranging from parents’ difficulties  
 618 securing an appointment, to transport and proximity to services, reflecting other research (13, 25,  
 619 44-46). Services were complex, fragmented and inconsistent in provision from place to place and  
 620 over time. HPs reported that they thought this complexity was a result of risk averse health service

621 cultures and algorithms that refer large numbers of children to hospital. Demand for services in  
622 primary care was reported to reduce relational continuity, which has been associated with a greater  
623 risk of emergency department use and hospitalization in children (47). A 2016 Royal College of  
624 General Practice report states that *'Patients who receive continuity of care in general practice have  
625 better health outcomes, higher satisfaction rates and the healthcare they receive is more cost  
626 effective'* whilst also reporting an increasing number of patients being unable to see their preferred  
627 GP (48).

628 Delay in accessing treatment for serious infectious illness has been associated with worse outcomes  
629 (49-51) and although the numbers of children involved in this study are too small to demonstrate  
630 such an association, the emergent theory does identify how such delays in accessing treatment  
631 happen, providing directions for future service developments and research.

## 632 **Strengths and limitations**

633 This is the first study in the UK, to our knowledge, to take a 360 degree approach (which included  
634 parents and professionals) to exploring the child's pre-hospital illness trajectory from becoming ill at  
635 home to being admitted to hospital with a serious infectious illness. The use of a modified grounded  
636 theory approach enabled the research team to generate an explanatory theory which integrates  
637 findings from across a diverse sample representing a range of different children's trajectories and of  
638 health professionals and services. The resulting theory has identified key factors which influence the  
639 timing of children's access to treatment for SII.

640 Unfortunately, it was not possible to make comparisons between the trajectories of children  
641 accessing the TH with those accessing the DGH in the study as so few families were recruited from  
642 the DGH site. This was unsurprising as the ambulance and HES data both showed much less activity  
643 at the DGH compared to the TH. Far fewer children were admitted to HDU at the DGH site during the  
644 recruitment period than expected. In addition, recruitment of first contact health professionals to



645 focus groups working in the area around the DGH was also low. As a result, comparisons could not  
646 be made between parents and/or health professionals' experiences.

647 We originally intended that all participants would be recruited from the two identified study sites so  
648 that comparisons could be drawn between the children's illness trajectories and the landscape of  
649 local services. Although we did recruit from our two study sites for Stage 1, in Stage 2 we were  
650 unable to recruit sufficient parents in these areas, instead recruiting nationally through our charity  
651 partners.

652 The intention of Stage 1 was to gather data from parents of children who had recently been  
653 hospitalised for a SII and from the health professionals involved in their care. However, the time  
654 delays involved made it challenging to gather data whilst events were still fresh in the HPs minds. No  
655 GPs were willing to take part in Stage 1. Fortunately, we were aware that some HPs might not want  
656 to discuss individual cases and had built in Stage 2 focus groups within which HPs were happy to  
657 discuss the experiences of caring for children with SII in general.

658 Choosing to take a 360 degree approach, exploring the whole of the child's pre-admission illness  
659 trajectory, meant that we were conducting research across multiple organisational boundaries  
660 within the NHS. Children's illness trajectories brought them into contact with six different services in  
661 two different counties. Access to these services needed to be negotiated separately. In addition, we  
662 worked with four charities and one parent support group. One of the strengths of this project is that  
663 the steering group reflected this complexity and we worked together to solve the issues, pooling our  
664 knowledge and expertise to keep the project on track.

## 665 Conclusions

666 The children's illness trajectories were often complex, particularly when a child was ill for more than  
667 48 hours prior to admission. Most parents reported accessing, or trying to access, primary care early  
668 in their child's illness trajectory. Missed opportunities for earlier treatment were identified between

669 these early primary care consultations and the development of severe illness. In this period of  
 670 uncertainty, parents and professionals described difficulties in recognising signs of serious illness.  
 671 Parents reported being uncertain of what symptoms to look out for as signs of deterioration and,  
 672 consequently, when to seek help, relying instead on significant change from their child's normal  
 673 before seeking help again. Medical staff sometimes reported finding it difficult to identify the  
 674 seriously ill child; this was made more difficult as the lack of relational continuity impedes  
 675 recognition of the degree of difference from normal.

676 Once parents present with their child to secondary care, they experience difficulties in  
 677 communicating their concerns to HPs and in being heard against a background of high levels of  
 678 demand in a hierarchical system where professionals hold all the power. Unequal power is also  
 679 reflected in parents' reported experiences of criticism at *every* stage of the trajectory, which they  
 680 tried to avoid by delaying seeking help until their child's illness could not be disputed.

681 The overriding message from HPs concerned the impact of high levels of demand for children with  
 682 low levels of illness. This demand, they thought, had increased as a direct result of overloaded  
 683 primary care, complexity of services, a risk-averse culture and health systems such as NHS111 which  
 684 have "*increased the size of the haystack*" making it difficult to identify the few children with serious  
 685 illness.

686 Most of the children in this study fell, at least in part, through the NHS safety-net, despite the risk  
 687 averse culture of services. In fact, this very risk averse system has created so much demand that it  
 688 makes it harder for professionals to identify the more seriously ill children from amongst the rest.  
 689 Although admonishments to use services appropriately do not appear to have reduced the overall  
 690 demand for services, such messages have resulted in increased parental uncertainty and anxiety  
 691 about re-consultation and consequently delaying seeking help until their child was very obviously  
 692 sufficiently seriously ill to validate re-presenting for care.

693 This mixed-methods project is the theory development stage required before a complex  
694 interventions study (52-54), to reduce modifiable factors that impact on children's journeys from  
695 becoming ill to hospital admission with SII, can be designed. The findings presented here indicate the  
696 need for interventions to increase parents and professionals' ability to recognise signs of serious  
697 illness, improve communication between parents and professionals in consultations and improve  
698 relational continuity. The findings also indicate a need for system level changes to safely reduce risk  
699 adverse systems which increase demand for urgent and emergency care services at low levels of  
700 illness.

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## 713 Data Sharing

714 Due to the sensitive nature of the research, we are unable to share the entire data set for the study  
715 and we do not have consent from parent participants to do so. Data extracts included in the paper

were carefully chosen to preserve participants anonymity and to conform with the participants consent.

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