Before Arrival at Hospital (BeArH) Factors affecting timing of admission to hospital for children with serious infectious illness project

NIHR RfPB Final Report

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A collaboration between the University of Northampton, Meningitis Now, Mother's Instinct Support Group, the University of Leicester, Edge Hill University, the University of Liverpool, the University of Plymouth, Kettering General Hospital NHS Foundation Trust, University of Leicester Hospitals NHS Trust and Northamptonshire Healthcare NHS Foundation Trust (NHFT)

In partnership with

Northamptonshire Healthcare NHS Foundation Trust

University Hospitals of Leicester NHS Trust

Kettering General Hospital NHS Foundation Trust

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Scientific Summary

Background and aim

Infection is a major cause of childhood deaths in the UK, particularly in the first 5 years of life. Modifiable factors were identified in 30% of child deaths in 2019. Understanding factors affecting children's pathways to hospital has become even more important during the pandemic: the number of children presenting to hospital has fallen, creating concern that more children may be receiving treatment late.

The aim of this project was to retrospectively identify organisational and environmental factors, and individual child, family, and professional factors affecting timing of admission to hospital for children under 5 years of age with a serious infectious illness (SII) in Leicestershire and East Northamptonshire.

Methods

A mixed methods design was used within a grounded theory methodology in collaboration with parents. We reviewed available child death reports, compared patterns of service use and services available to children between areas (Stage 1), followed by two stages of data collection (Stage 2). In Stage 2a we interviewed 22 parents whose child had recently been hospitalised with a SII and 14 health professionals (HPs) involved in their pre-admission trajectories. In 2b we conducted separate focus groups with 18 parents and 16 first contact HPs with past experience of childhood SII. The analysis integrated all of the findings.

Key findings

The core category/finding was identified as 'navigating uncertain illness trajectories for young children with serious infectious illness'. Uncertainty was prevalent throughout the parents' and HPs' stories about their experiences of navigating social rules and health services for these children. The complexity of services, family lives, social expectations and hierarchies, provided the context and conditions for children's, often complex, illness trajectories. Factors influencing these trajectories were: uncertainty, knowledge and experience, overburdened services and the lack of continuity of HP. Parents, in particular, reported feeling powerlessness, loss of control and perceived criticism leading to delayed help seeking. Importantly, parents and professionals miss symptoms of serious illness. Risk averse services refer more children to emergency care, increasing the burden on services, making it more difficult for HPs in emergency departments (EDs) to spot the seriously ill child.

Outputs, impact and dissemination

Our systematic review has been submitted for publication. Findings will be disseminated in professional and parent-facing media after the report is published.

Conclusions

Most parents reported accessing, or trying to access, primary care early in their child's illness. Missed opportunities for earlier treatment were identified between these initial primary care consultations and the development of severe illness. Parents and professionals have difficulties recognising signs of SII in young children and parents feel socially constrained from seeking help. Most of the children in this study fell, at least in part, through the NHS safety-net, despite the risk averse culture of services.

Future plans

Projects planned: a study of parents' consultations with HPs to identify causes of perceived criticism; and a feasibility study for a safety-netting app. Further research is needed to explore how to reduce the complexity of services and improve continuity of HP involved in each child's care.

Key words

Child; delayed treatment; grounded theory; illness trajectories; parent; health professional; serious infectious illness; timely treatment

Plain English Summary

Infection is a major cause of childhood illness and death from 0-5 years. In the early stages of illness it is difficult to know which children will become seriously ill. If health professionals (HPs) are to prevent avoidable child deaths, there must be greater understanding of what influences the decisions parents and professionals make when a child is sick, before hospital admission.

Working in collaboration with parents, our project team aimed to identify all of these influences to inform the development of strategies that ensure children with serious infectious illness (SII) get appropriate timely help.

The study took place in a district general hospital, a teaching hospital and their respective catchment areas.

We examined existing evidence about services, service use and lessons learned from investigations concerning children with SII. We interviewed 22 parents whose child had been in hospital with a SII and 14 HPs who the parents consulted before their child was admitted. We also conducted focus groups with 18 parents whose child had had a SII and separately with 16 HPs with experience of caring for such children.

Most parents interviewed sought help from a GP early in their child's illness. Missed opportunities for earlier treatment were identified between these consultations and the development of severe illness. In this period of uncertainty, parents and professionals have difficulties recognising signs of serious illness and parents worry about asking for help again. Professionals were uncertain about how to avoid missing really sick children. Children with SII continue, at least in part, to fall through the NHS safety-net.

We will share our findings with parents and professionals. Our review of previous studies has been submitted for publication. We are planning more projects to: improve parents' experiences with health professionals; and improve parents' and professionals' ability to recognise important symptoms.

Aims and Objectives

Aim

To retrospectively identify organizational and environmental factors and individual child, family and professional factors affecting timing of admission to hospital for children with serious infectious illness (SII) in Leicestershire and East Northamptonshire.

Research questions

The research questions of this project were to identify:

1. What, if any, social and/or personal child and family characteristics influence the journeys of children with serious infectious illness from home to hospital admission?
2. What, if any, modifiable organizational, environmental and individual human factors within health services affect the timing of the journeys of children with serious infectious illness from home to hospital admission?
3. What differences, if any, are there between the illness journeys of children with serious infectious illness treated promptly and those who would have benefited from earlier treatment?

Answering these questions is the theory development stage [1, 2] which would lead to further work to develop a complex intervention designed to reduce modifiable factors (e.g., delays in presentation) that impact on children's journeys from becoming ill to hospital admission with SII. Insufficient evidence exists to develop evidence based interventions, making this project an essential step towards addressing modifiable factors in these children's journeys to hospital admission.

Background

Infection is a major cause of childhood deaths in the UK and globally, particularly in the first 5 years of life. In the East Midlands 28,929 children (27.9% of all admissions) were admitted with infectious illness between 2011-2014, the largest group of emergency hospital admissions by ICD coding [3]. Between 1999 and 2010 emergency admissions for children increased significantly, particularly for under 5s (<1s by 52%, aged 1–4 by 25%) and acute infections (by 30%) [4]. This trend continued between 2007 and 2017 with a 1.6%/year increase in emergency department visits for all children and 3.9%/year for infants [5]. The Confidential Enquiry into Maternal and Child Health [6] report found that infectious illness was 'the single largest cause of death in children dying of an acute physical illness' (p14) constituting '20% of the deaths overall' (p31) with 1-4 year olds most affected. Many of these deaths are avoidable as infections such as pneumonia and meningococcal disease are amenable to treatment, if provided in time [7].

Child Death Reviews (CDR), which aim to identify modifiable factors in any child's death, are reported by Local Safeguarding Children's Boards and collated into annual reports for England

by NHS Digital since 2018, previously by the Department for Education [8]. In the year ending March 2019, modifiable factors were identified in 30% of all child deaths and 38% of deaths from infection [9]; an increase from 24% of all child deaths in 2016 [10]. More problematic is the reporting of seriously ill children who could have been treated sooner. These should be reported as patient safety incidents through the National Reporting and Learning System (NRLS); however, there are few returns from primary care leading to limited learning about influences on pre-hospital care. These systems depend on recorded data; consequently, human factors are rarely captured. Notably families appear to be absent from such data collection and parents report difficulties in securing the engagement of health services in learning from their children's deaths (www.mothersinstinct.co.uk).

This project addresses the national agenda to improve child health outcomes [11-14] as it focuses on the drive to understand factors contributing to avoidable deaths through exploring the child's journey from becoming ill to hospital admission – a missing piece of the jigsaw.

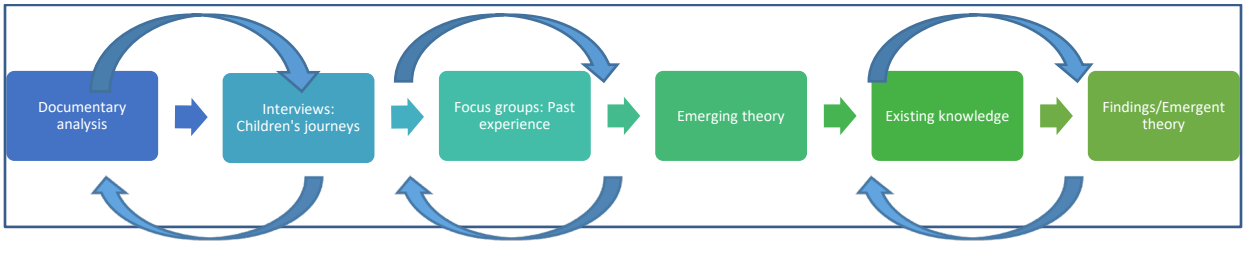
Understanding factors impacting on children's journeys to hospital is now (in May 2020) even more important as the number of children presenting to hospital has fallen significantly during the pandemic, leading to concerns that more children may be receiving treatment late in the course of their illness. Findings from this project provide important insights into the complex interplay of parent, professional and organisational factors influencing the timing of treatment for these serious infectious illnesses.

Method

An explanatory two stage mixed methods design (Appendix 1 Gantt chart) was used [15] within a grounded theory (GT) methodology [16] (See Figure 1).

- Stage 1: Documentary analysis of existing evidence
- Stage 2: Data collection and analysis:
    - 2a Individual children's journeys to hospital admission;
    - 2b Past experiences of parents and professionals of children's journeys.

Figure 1 Explanatory mixed methods grounded theory design



Stage 1

The documentary analysis aimed to map identified modifiable factors in reports concerning child deaths in each area, compare between areas in the context of patterns of service use and services

available to children, to identify patterns for exploration in Stage 2. Data access was limited to publicly available data on the child population, first contact urgent care services, healthcare episode statistics and ambulance service use in each area. Data on child deaths was only available for Leicestershire. No information was available on modifiable factors identified from child death reviews.

Ethical considerations

The project received ethical approval from East Midlands – Nottingham 1 Research Ethics Committee (17/EM/0334) on 8th November 2017 and nine subsequent amendments were approved. Confirmation of capacity and capability (C&C) was received from the participating NHS sites (Appendix 2).

Stage 2

Study areas

The two study areas were a District General Hospital (DGH) and a Teaching Hospital (TH), and their catchment areas, as these two East Midlands areas are representative of patterns of health services provided for most children in England.

Recruitment

Seventy-one participants were recruited (11th January 2018 - 31st October 2019), with a 6-month suspension (May-November 2018). For details of recruitment, see the study protocol.

Stage 2a

Parents whose children, aged between 1 month and 5 years, had received care in a paediatric intensive care or high dependency unit for at least 48 hours with a diagnosis of infection were recruited following transfer to a children's ward. Twenty-two parents and one neighbour (translator) were interviewed following discharge; three families from the DGH and nine from the TH (Table 1). Health professionals (HPs) involved in these children's pathways to hospital were interviewed for two children from the DGH site and three children from the TH site (Table 2). No general practitioners (GPs) or nurse practitioners (NPs) involved in these children's pre-hospital care were available.

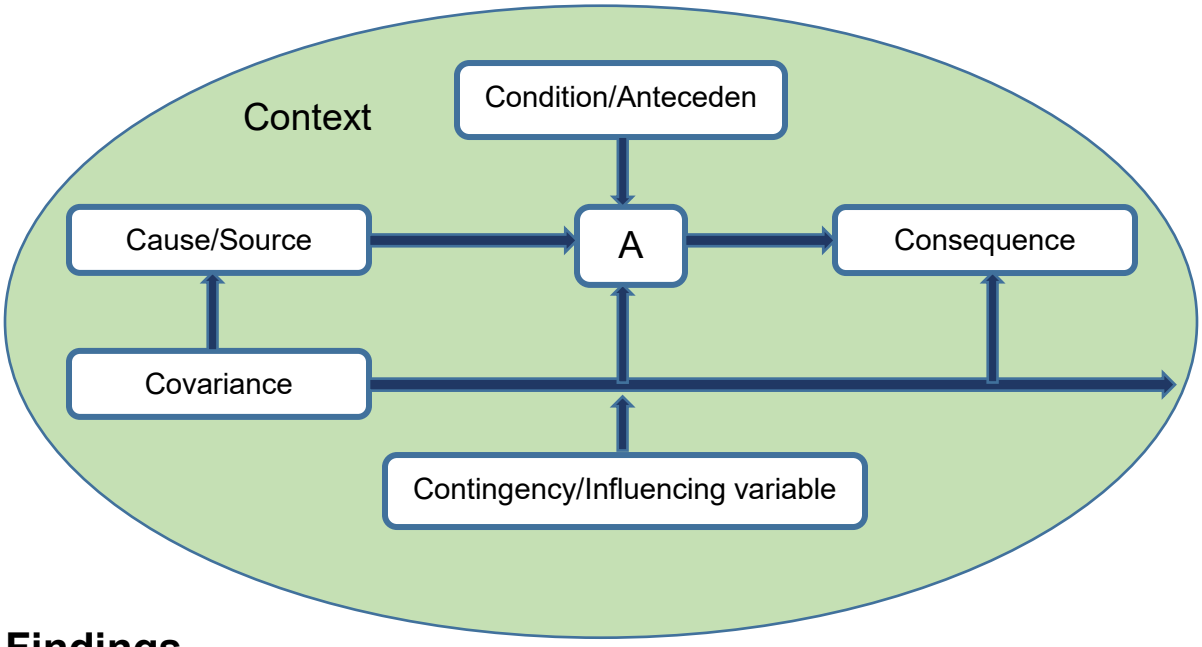
Stage 2b

Three focus groups were conducted with parents whose child had had a SII between 2011 and 2018 and, separately, with HPs who had experience of caring for such children in first contact services (Tables 3 & 4).

Data collection and analysis

Data were analysed using the constant comparative method [17], including drawing timeline diagrams depicting each child's pathway to hospital admission. Glaser's 6 Cs coding frame (Figure 2) facilitated the identification of, and interrelationships between, factors influencing children's pathways, explaining children fell through the NHS safety-net. Once the emerging theory had been identified, its fit with existing knowledge, including our systematic literature review [18], was explored.

Figure 2 Glaser's (1978) 6C's coding family



Findings

Stage 1 findings

Analysis of documentary evidence identified higher deprivation in inner city/urban than in rural areas within both study areas. Variable patterns of health service provision were reflected in patterns of health service use, with lower rates of emergency department (ED) attendance in areas provided with more urgent care centres. Younger children use more hospital care; hospital use is higher in the winter months. Ambulance service use was higher in the area surrounding the TH than the DGH. Low levels of presentation to DGH by ambulance reflected the low numbers of children eligible for the study from that site. No information was available from child death reviews concerning modifiable factors; it was not possible to look for the existence of these factors in our data. Appendix 3 details Stage 1 findings.

Stage 2 findings

Navigating uncertain illness trajectories for young children with serious infectious illness

Uncertainty ran throughout parents and health care professionals' stories of navigating social rules and health services to enable these children to access treatment in a timely manner. Navigating is defined as '*finding one's way through, along, over or across something'* [19] illustrating the multiple pathways through complex services. If the NHS is conceptualised as a safety-net, most of the children in this study have fallen, at least in part, through this safety-net.

The Context: the family and the health services

The family

Families lead busy lives (Tables 5 & 6), sometimes delaying seeking help to care for other children (THP010, THP012). Fewer parents reported seeking help/advice from people in their network than is reported in earlier research [20-22], instead managing the illness within the immediate family unit, reflecting other findings [23].

The complexity and variability of health services

Urgent and primary care services differed between geographical areas (See Appendix 3), leading to confusion - parents and HPs reported that they do not always know where to go, at what level of illness. HPs reported a lack of consistent advice for parents.

This complexity of services was thought by HPs to be a consequence of risk averse cultures and algorithms that refer large numbers of children to hospital. This increase was described as creating '*noise*' making it hard to identify the few seriously ill children. One ED doctor summed up the situation: *'we have made the haystack bigger. There is still only one needle but the haystack is enormous.'*

Antecedents or Conditions: social expectations and social hierarchies.

Social expectations

Social expectations create moral frameworks for behaviour that are learnt through our interactions with others [24, 25]. Parents and HPs' moral frameworks differ [26]; parents report moral responsibilities to protect their child *and* use services only when necessary, while HPs report a moral responsibility to control demand for services. Expectations are often uncertain. Acting outside of these moral codes requires courage as perceived transgression may result in those actions being criticised [24].

Social hierarchies

The unequal power created by social hierarchies was evident in parents and HPs' accounts of their interactions in this and prior research [27]. Parents' powerlessness was seen in their distress when they were unable to secure help for their child, while power was evident in HPs' accounts of managing demand and in gatekeeper roles. Professionals hold privileged knowledge that parents rely on, while parents' expertise on their child was reported to be ignored.

The illness trajectory

Defining the illness and its severity

As in earlier work [21, 23, 28], parents' ability to define the illness and judge its seriousness is affected by: tiredness, distractions of family life, past experience, knowledge of symptoms/illness and not wanting it to be serious ('*the thought of it being something more is unbearable.*' DFG5). In the later stages of the trajectory, parents reported that something was obviously *'not right'.* Before this point lay uncertainty about the legitimacy of seeking help; this uncertain part of the illness trajectory presents opportunities for earlier treatment.

Some symptoms of serious illness were not recognised (Box 1) and the significance of parents' phrases describing their unwell child (Box 2) were reported to be missed by HPs.

Parent help seeking during the illness trajectory

Parents made 1-6 contacts with health services during the illness trajectory - see Tables 7, 8, 9 & 10. Use of OOHS was rarely reported. Access to GP appointments, to transport and proximity to services, affected children's trajectories, reflecting other research [29-32].

Box 1 Missed symptoms of serious illness

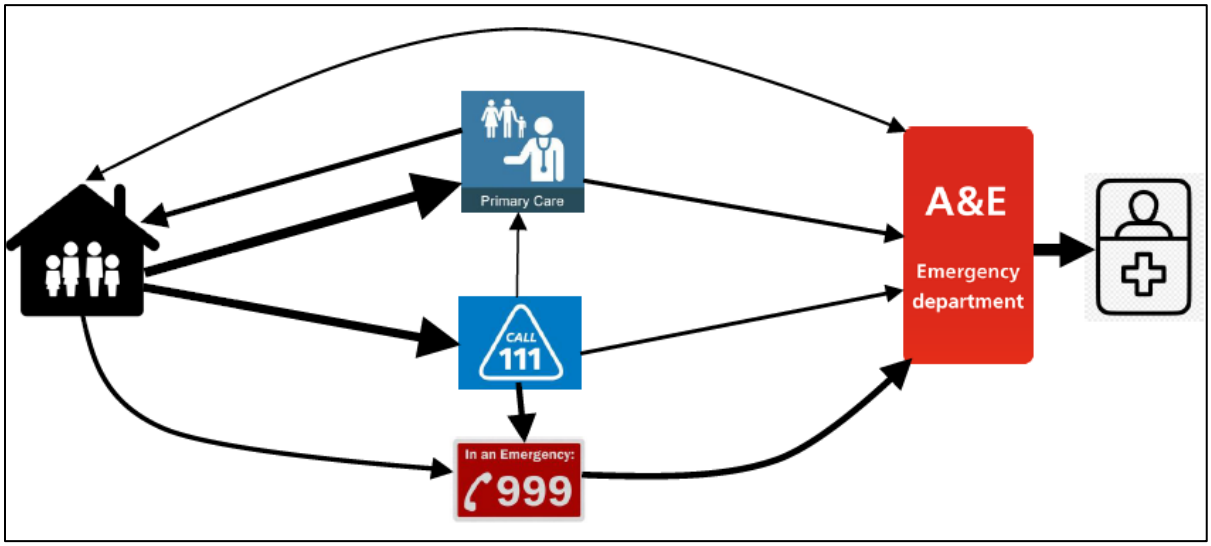
Symptoms not recognised by parents	**Symptoms not recognised by health professionals**
• Head/back pain • Mottled skin • Sucking in under the ribs • Fast breathing • Grunting • Funny cry • 'Bruising', 'love bite', purple mark • Staring • Stiffness • Temp over 38 in young baby • Lack of urine • Non-response to paracetamol	• Purple mark (NHS 24 call handler) • Temp over 38 in young baby (Out-of-hours service (OOHS) GP) • Lack of urine (OOHS GP) • Grunting (ED doctor)

Box 2 Phrases used by parents to describe their unwell child.

Not himself/herself Not there behind the eyes Not interested in anything This doesn't seem right That doesn't look right

The children's trajectories were often complex, particularly when the child was ill for longer before admission. Figure 3 shows the pathways of service use with thicker arrows for more common illness trajectories.

Figure 3 Pathways to hospital admission



Influencing variables or Contingencies

Uncertainty

Several forms of uncertainty were present in the data. Diagnostic uncertainty (not knowing what is wrong); symptom uncertainty (not knowing what symptoms to expect); trajectory uncertainty (not knowing the course of the illness); and symbolic uncertainty (how behaviour will be viewed by others). Earlier parental research identified all these forms [33-35]; in the findings reported here, health professional uncertainty (diagnostic and trajectory) was identified for the first time.

Knowledge and experience

Parent's knowledge of their child, 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)*'* DGHP02), influenced their decision making, as seen in other research [23, 27].

A HP's knowledge influenced their ability to identify signs of SII. Where HPs had less child specific education, they relied on personal experience 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/when parents sought help (MIDPFG1M1, THP012, THP018).

Number of children presenting to services

All HP participants talked about the difficulties of the number of children presenting to services. This 'noise' creates an expected pattern that every child has a minor illness ('*just another one of them*' HP09 ambulance technician).

Relational continuity

Continuity of relationship between the family and their GP/NP was reported to help HPs recognise differences from the child's normal. However, limited continuity meant that HPs had no pictorial memory of the child (e.g. LRIP005). GPs reported that managing 'demand' has reduced relational continuity, although this was justified with reference to the value of '*fresh eyes on the problem'*.

Consequences

Powerlessness and loss of control

Parents experience a loss of control before they seek help: *'I'm the Mum, I should be able to make my child better, but I couldn't'* (LONPFGM1). Unequal power between parents and HPs increased parents' powerlessness and their struggle to be heard. One ED doctor explained that *'I don't think you should necessarily be influenced that much by what they (parents) say.'* (THHPFG2-ED Doctor). Some parents thought their difficulties in being heard were related to being labelled ('*panicky first time parents*' DGHP001), or to difficulties describing symptoms.

Parents reported having to provide incontrovertible evidence of their child's symptoms (e.g. for professionals to see/hear symptoms (THP005, THP022, MIDPFG1M2)), before their concerns were taken seriously. Desperation was evident in the accounts of parents whose concerns were not addressed.

Perceived criticism and delayed help seeking

Parents who had experienced criticism for using services early in the illness, delayed seeking help (e.g. DGHP01, THP027, MIDPFGM2) to avoid further criticism from those in positions of power [20, 22, 30, 36-38]. Parents' reluctance to re-consult was influenced by HP's reassurance that nothing was seriously wrong with their child *('being sent back home by the GP made us think we are supposed to deem this normal'* THP005).

'Layers of risk' and risk management

In primary care, GPs referred to '*layers of risk*' (THHPFG1 GP) - from what symptoms parents' report during phone calls to the practice, to the consultation itself - all contributing to uncertainty. HPs felt that managing this uncertainty via risk averse organisational systems (e.g. NHS111 algorithms) had increased the burden on services. HPs reported providing safety-netting advice to families but parents recalled this advice as '*if she gets worse bring her back'* (MIDPFG2M1), '*But what is 'worse'*?' (MIDPFG2M3).

Courageousness

Parents demonstrated courageousness in persisting in raising concerns, often in the face of criticism and disbelief. Sometimes it took a deterioration in their child's condition to legitimate their concerns.

Conclusions

The children's trajectories were often complex, particularly when the child concerned was ill for more than 48 hours prior to admission. Most parents reported accessing, or trying to access, primary care early in the course of their child's illness. Missed opportunities for earlier treatment were identified between these early primary care consultations and the development of severe illness. In this period of uncertainty, parents and professionals have difficulties recognising signs of serious illness. Parents reported being uncertain of what symptoms to look out for as signs of deterioration and, consequently, when to seek help, relying instead on significant change from their child's normal before seeking help again. Medical staff reported finding it difficult to identify the seriously ill child; this is made more difficult as the lack of relational continuity impedes recognition of the degree of difference from normal.

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

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

Most of the children in this study fell, at least in part, through the NHS safety-net, despite the risk averse culture of services. In fact, this very risk averse system has created so much demand that it makes it harder for professionals to identify the more seriously ill children from amongst the rest. Admonishments to use services appropriately do not appear to have reduced the overall demand for services, such messages have resulted in increased parental uncertainty and anxiety about

re-consultation and consequently delay in seeking help until the child was very obviously sufficiently seriously ill to validate re-presenting for care.

It was not possible to make comparisons between the trajectories of children accessing the TH with those accessing the DGH in the study as so few families were recruited from the DGH site. Far fewer children were admitted to HDU at the DGH site during the recruitment period than expected. In addition recruitment of first contact health professionals to focus groups working in the area around the DGH was also very low. As a result comparisons could not be made between parents and/or health professionals' experiences.

Intellectual Property, Commercialisation and Clinical Adoption

Findings from the project will be used to demonstrate the need for, and funding applications for, a mobile app and associated training packs for parents and professionals designed to improve the ability to recognise signs of serious illness in children <5 years. Research team members are also members of the UK Safety Netting Collaborative who have developed the content for an app. The intellectual property for the app resides with the members of the UK Safety Netting Collaborative/ASK SNIFF team.

Intellectual property generated directly from this project will be limited to the academic papers the project team produce.

Actual and Anticipated Impact

Brief impact statement

Our key impact is creating an evidence base that shows the following contribute to a delay in the admission of children to hospital with a serious infectious illness: parents concern that they will be criticised for using services unless the illness is serious, parents and professionals missing signs of serious illness; and risk averse health systems increasing health service use making it difficult for professionals to identify seriously ill children. This is the theory development stage for future complex intervention development to improve parents and professionals interactions and the identification of symptoms of serious illness in children.

Describe the impact the research has already achieved on might achieve in the short, medium and long term

This is a qualitative research project designed to develop an understanding of the factors which affect the timing of admission to hospital of children under 5 years of age with serious infectious illness. Therefore the trajectory to patient benefit is longer than would be the case for an intervention study. This study represents the theory development stage [1, 2] for a complex intervention designed to reduce modifiable factors (e.g. delays in presentation) that impact on children's journeys from becoming ill to hospital admission with SII.

Immediate impact

Awareness of this study has led to this research group being involved in the dissemination of videos related to safety-netting embedded within the Healthier Together website, RCPCH advice for parents during the pandemic https://www.rcpch.ac.uk/sites/default/files/2020-04/covid19_advice_for_parents_when_child_unwell_or_injured_poster.pdf and the development of a survey for parents to understand changes in consultation patterns for children during the lockdown https://wh1.snapsurveys.com/s.asp?k=158885348067. Through these mechanisms study findings have been used in the development of pathways of care during the COVID-19 pandemic to ensure that the impact of collateral damage is reduced.

Short term impact

Short term impact will include dissemination of findings through ongoing conversations around safety-netting, consultation practices and in publications starting with our systematic review. From the beginning of the project we have raised awareness of the study through the media (at the launch of the project), the project website https://www.northampton.ac.uk/research/before-arrival-at-hospital-bearh/ and team members institutional websites (e.g. https://www.plymouth.ac.uk/research/institutes/health-community/maternal-and-family-health-research-group/before-arrival-at-hospital-bearh-project). The findings will be shared through the media once the report has been approved by NIHR.

Medium term impact

Findings from the project will: support the involvement of parents/carers in the development of pathways of care when improving management of 'febrile care'; improve the understanding of the relative paucity of cases of SII; and increase understanding that sepsis is not 'everywhere'. The findings raise awareness that measures need to be put in place to reduce harm from potential delays in seeking help, leading to the development of interventions to improve parents and professionals' knowledge of the signs of serious infectious illness in children and further research to improve the quality of interactions between parents and professionals.

Dissemination of our findings concerning the complex interplay of risk averse systems creating increase in health service use for low levels of illness will impact on policy development concerning the development and delivery of services for children.

Dissemination

During the project, dissemination has been ongoing; from the involvement of the media in the launch of the project, to our project website, to conference presentations focusing on methodology and engagement with our professional networks. We plan for heightened intensity of dissemination activity on completion of the report to focus on our findings. Social media will be used to highlight specific findings and disseminate the NIHR publicly available version of the report once this has been approved and made available by the RfPB. Our charity partners will be encouraged to announce the publication of the report on their websites and social media sites. Members of the BeArH PMG will disseminate key findings through their professional networks,

nationally and internationally. Our lay summary will be shared with relevant charities and health services. Study reports will be shared with members of the Advisory Group and with wider stakeholders and health policy makers such as the RCPCH, RCN, iHV, Healthier Together, NHS England and Health Education England. We also plan to disseminate our findings through the traditional professional routes and through parent facing media (See Appendix 4). Parents have already collaborated on writing the lay summary and they will be invited to be involved in writing all publications. Parents will be central to the production of all parent facing media.

Public engagement - prior to the pandemic we had planned a multimedia event to present the results of the study to the public in collaboration with our NGO and charity partners (Mother's Instinct, Meningitis Now, Meningitis Research Foundation, Sepsis UK and WellChild). The planning for this event has been postponed in the light of the Covid19 pandemic. All of the participants who have requested feedback on the findings of the research will be sent the executive summary of findings with the option to contact the Chief Investigator for a copy of the full report.

Once the pandemic has abated and social distancing guidance removed, we will plan a series of conference presentations and workshops. The latter will be offered to both of the hospitals involved in recruiting parents and professionals to the study and to first contact services in both areas. Should the requirement for social distancing continue, we will explore options for virtual conference presentations and webinars.

Publications

Our systematic review was submitted to PLOS ONE in April 2020. Title: A systematic review of the organizational, environmental, professional and child and family factors influencing the timing of admission to hospital for children with serious infectious illness.

We also plan the following papers for submission to high quality peer-reviewed journals:

- Getting the whole picture: designing studies to capture 360 degree data on family health service use.
- Dissonance between what is found in the real world and the narratives around tragedies.
- Barriers to recruitment created by ethical approval processes.
- Uncertain illness trajectories: parents' experiences of seeking help for a child with a serious infectious illness
- Young children's uncertain illness trajectories – professionals' experiences of risk and uncertainty
- Complex health services for the sick child: impact on timely treatment for serious infectious illness
- An exploration of the fragmentation of healthcare
- Technology used by parents
- Working together: the value of embedding PPI in parent research.

We also plan to reach out to the general public through our charity partners and through publishing in fora such as The Conversation. See Appendix 4 for our Publication Plan.

Patient and Public Involvement

BeArH team members have long-standing relationships with parents/patient advocacy groups. Consequently it was natural that patient and public involvement (PPI) would be embedded throughout this project. Patient advocates (parents with lived experience of children with a SII, or representing support groups for such parents) were recruited to the project team at the beginning of proposal development.

Aims

The aims of patient and public involvement in this project were:

- to ensure active involvement of parents and relevant patient groups in the research at each stage of the project
- to ensure that the project was planned, delivered and reported sensitively, in ways which optimised parent recruitment and participant comfort during the process,
- to ensure that it remained relevant and appropriate to parents of children with serious infectious illness.
- to ensure active involvement of patient groups and the public in research so that it stays relevant and appropriate to the priorities of those the research seeks to benefit.

Methods

Parents directly affected by having had a child with a SII and charities who support families affected by SII were recruited to both the Programme Management Team (PMT) and the Advisory Group (AG). These parents/support charities:

- helped shape the project proposal as they were involved from the inception of the project idea
- helped shape the research planning, design and management of the project
- provided guidance and grounding in PMT and AG meetings, helping the other members of the project team to more authentically understand and prepare for engaging with parents in interviews and focus groups
- taught the other members of the team about emotional touch points and in doing so enhanced the team's sensitivity to parents' needs
- provided resources and training for research staff to understand the impact of SII on parents/carers of a young child
- helped recruit participants to the research project
- contributed to the writing, reporting and dissemination of research findings.

Study results

Both the PMT and AG had regular meetings and interim communications within which our PPI representatives were actively engaged in providing direction for the team, feedback and discussion about parent perspectives. Training was delivered to the clinical research nurses involved in recruiting to the project and project researchers, resulting in improved understanding of, and empathy for, this group of parents.

Our PPI representatives provided extensive input to written documents to ensure the wording was sensitive and relevant for parents - most suggestions were included/incorporated. Patient support charities assisted with the recruitment of parents/carers for focus groups, leading to 18 parents participating in three parent focus groups and several telephone/email interviews.

Discussion and conclusions

The project was richer, more informed, more courageous and more insightful as a direct result of the involvement of people with personal experience of children with SII. It was designed by people already very experienced in communicating with parents on such sensitive topics; PPI allowed for refinement of those elements needed to carry out the proposed plans.

Involvement of PPI representatives throughout the project allowed for the voices of those directly impacted by childhood SII to be heard at every stage of planning and research. It allowed for parent recruitment strategies and materials to be refined to ensure they spoke directly, sensitively and appropriately to the intended audience. The involvement of a variety of PPI representatives also made sure that parents of children with a range of outcomes and experiences were considered when contemplating recruitment strategies.

Reflective/critical perspectives

The project gave a voice to those families affected by childhood SII, and was conducted as sensitively as possible, by ensuring PPI from the start. The PMG and AG members consisted of a broad range of charity/patient members, which led to a good breadth of knowledge and input, with extensive recommendations for written materials, and interview/focus group approach, the majority of which were implemented.

There was some conflict between the way materials needed to be designed to be compliant with ethical approval requirements and the way PPI partners recommended the materials be written for their platforms. In future, clearer communication guidelines and earlier involvement of the communications experts from each partner would lead to the development of draft documents prior to ethical approval suitable for a variety of platforms, which may have resulted in more effective recruitment to the focus groups.

Future research plans

Ambulance crew and call handlers in NHS111 and 999 would benefit from further education in the assessment of acutely ill children, while doctors and nurses would benefit from the development of professional skills in attending to, and addressing, parents' concerns. As one ED doctor expressed it '*So, when the parent comes in concerned because their child is different, it's at our peril if we dismiss that. We may know more medicine, but we don't know their child*.' (THHPFG1), emphasising the importance of recognising and acknowledging parents as the expert on their child. The repeated reports of parent(s) being criticised in encounters with HPs needs further research to establish what is perceived as criticism and how this can be avoided in future.

Parents and HPs miss signs of serious illness - requiring information resources to facilitate learning. Safety-netting for use during and after consultations should be standard practice but it needs to be in a form that is accessible for, and comprehensible to, parents. One parent commented *'to see pictures of what that looks like could really help'* (MIDPFG2M1). Educational resources for parents and medical professionals could improve recognition of signs of serious illness – one of the key barriers to accessing timely treatment.

We plan a feasibility study to determine whether a mobile app and associated training packs for parents and HPs designed to improve ability to recognise signs of serious illness in children under 5 years of age can improve knowledge and confidence in identifying the signs of serious illness. This study will also assess whether the app will also improve parents' confidence in home management at lower levels of illness and improve timely consultation for serious infectious illness. Research team members are also members of the ASK SNIFF group who have developed the content for an app.

An exploratory project to identify factors affecting the quality of interactions between parents and professionals is also planned. This project will explore how to improve parents' ability to be heard and professional ability to respond to parents' concerns. This is the missing piece of the jigsaw needed to address parents' experiences of criticism.

Organisationally further research is needed to:

- Explore how to improve the sensitivity of algorithms to degrees of severity of illness in children and consequently to reduce unnecessary ambulance call outs and visits to ED; and
- Determine how to reduce the complexity of services, improve relational continuity and communicate effectively with the public about services available in any one area.

Data Sharing

Access to and use of study data

Study data will be held in a secure central storage facility at the University of Northampton for up to 10 years and then destroyed.

- All members of the PMG may use the study data, but will need to contact the original CI (SN) to arrange access through the University of Northampton Records Manager (currently Phil Oakman).

- Any use of study data, including process and outcome data, beyond the study team must be subject to prior approval from the PMG, which must include both CIs.

- Requests from outside the PMG must be in writing and clearly describe the purpose for which the data is required and how it is to be used.

- Once the PMG have approved access to the study data, one of the CIs will forward the request to the University of Northampton Records Manager (currently Phil Oakman) who will arrange access to the data.

- All output from such work must acknowledge the source of the data, and its use must be consistent with ethical and governance approval (either existing or subsequently sought).

References

1. Medical Research Council (MRC), *A Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health*. 2000, Medical Research Council: London.
2. Medical Research Council (MRC), *Developing and evaluating complex interventions: new guidance*. 2008, Medical Research Council: London.
3. Gill, S., *Where do East Midlands' Children and Young People get admitted and for what? Paediatric Inpatients and Health Care Provider Destination in The East Midlands: 2011 to 2014. Draft report*. 2015, Knowledge and Intelligence Service, East Midlands in partnership with East Midlands Women and Children's Network,.
4. Gill, P.J., et al., *Increase in emergency admissions to hospital for children aged under 15 in England, 1999-2010: national database analysis.* Archives of Disease in Childhood, 2013. **98** (February 11, 2013): p. 328-334.
5. Ruzangi, J., et al., *Trends in healthcare use in children aged less than 15 years: a population-based cohort study in England from 2007 to 2017.* BMJ Open, 2020. **10**(5): p. e033761.
6. Confidential Enquiry into Maternal and Child Health (CEMACH), *Why Children Die? A pilot study 2006. England (South West,North East & West Midlands), Wales and Northern Ireland*. 2008, National Children's Bureau: London.
7. Wolfe, I., et al., *Improving child health services in the UK: insights from Europe and their implications for the NHS reforms.* BMJ, 2011. **342**: p. d1277.
8. Wolfe, I., et al., *Why children die: death in infants, children and young people in the UK Part A*. 2014, Royal College of Paediatrics and Child Health, National Children's Bureau & British Association for Child and Adolescent Public Health London.
9. Community and Mental Health Team NHS Digital, *Child death reviews: year ending 31 March 2019. Analysis from the Local Safeguarding Children Boards (LSCB1) Child Death Review Data Collection* 2019, The Health and Social Care Information Centre, NHS Digital.
10. Department for Education, *Statistical First Release. Child Death Reviews – Year ending March 2016*. 2016, Department for Education: London.
11. Bardsley, M., et al., *Is secondary preventive care improving? Observational study of 10-year trends in emergency admissions for conditions amenable to ambulatory care.* BMJ Open, 2013. **3**(1): p. e002007.
12. Kossarova, L., D. Devakumar, and N. Edwards, *The future of child health services: new models of care*. 2016, Nuffield Trust: London.
13. Lewis, I. and C. Lenehan, *Children and Young People's Health Outcomes Strategy. Report of the Children and Young People's Health Outcomes Forum*. 2012, Department of Health: London.
14. Royal College of Paediatrics and Child Health, Royal College of Nursing, and Royal College of General Practice, *Facing the Future: Together for Child Health*. 2015, Royal College of Child Health: London.
15. Creswell, J.W. and V.L. Plano Clarke, *Designing and Conducting Mixed Methods Research*. 2nd edition ed. 2011, Thousand Oaks, California: Sage.
16. Glaser, B. and A. Strauss, *The discovery of grounded theory: strategies for qualitative research.* 1967, New York: Aldine De Gruyter.
17. Glaser, B., *Emergence vs Forcing. Basics of Grounded Theory Analysis*. 1992, Mill Valley, California: Sociology Press.

18. Carter, B., et al., *A systematic review of the organizational, environmental, professional and child and family factors influencing the timing of admission to hospital for children with serious infectious illness.* Submitted March 2020.
19. Robinson, M., *Chambers 21st Century Dictionary*. 1996, Edinburgh: Chambers.
20. Ingram, J., et al., *Parents' information needs, self-efficacy and influences on consulting for childhood respiratory tract infections: a qualitative study.* BMC Family Practice, 2013. **14**(1): p. e106.
21. Neill, S., et al., *Parent's information seeking in acute childhood illness: what helps and what hinders decision making?* Health Expectations, 2015. **18**(6): p. 3044-3056.
22. Turnbull, J., et al., *A conceptual model of urgent care sense-making and help-seeking: a qualitative interview study of urgent care users in England.* BMC Health Services Research, 2019. **19**(1): p. e481.
23. Neill, S., *Containing acute childhood illness within family life: A substantive grounded theory.* Journal of Child Health Care, 2010. **14**(4): p. 327-344.
24. Goffman, E., *The Nature of Deference and Demeanor*, in *Interaction Ritual. Essays on Face to Face Behaviour*, E. Goffman, Editor. 1972, Penguin Harmondsworth.
25. Stokes, T., M. Dixon-Woods, and S. Williams, *Breaking the ceremonial order: patients' and doctors' accounts of removal from a general practitioner's list.* Sociology of Health & Illness, 2006. **28**(5): p. 611-636.
26. Ehrich, K., *Reconceptualizing 'inappropriateness': researching multiple moral positions in demand for primary healthcare.* Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 2003. **7**(1): p. 109-126.
27. Neill, S.J. and I. Coyne, *The Role of Felt or Enacted Criticism in Parents' Decision Making in Differing Contexts and Communities: Toward a Formal Grounded Theory.* Journal of Family Nursing, 2018. **24**(3): p. 443-469.
28. Neill, S., S. Cowley, and C. Williams, *The role of felt or enacted criticism in understanding parent's help seeking in acute childhood illness at home: A grounded theory study.* International Journal of Nursing Studies, 2013. **50**(6): p. 757–767.
29. Crocker, J.C., et al., *Why some children hospitalized for pneumonia do not consult with a general practitioner before the day of hospitalization.* European Journal of General Practice, 2013. **19**(4): p. 213-220.
30. Francis, N., et al., *Missed opportunities for earlier treatment? A qualitative interview study with parents of children admitted to hospital with serious respiratory tract infections.* Arch Dis Child, 2011. **96**(2): p. 154 - 159.
31. Hodkinson, P., et al., *Pathways to Care for Critically Ill or Injured Children: A Cohort Study from First Presentation to Healthcare Services through to Admission to Intensive Care or Death.* PLoS ONE, 2016. **11**(1): p. e0145473.
32. Young, N., *The pre-hospital experiences of Samoan families who have had a child admitted to hospital with pneumonia: a qualitative investigation.* Pacific Health Dialog, 2001. **8**(1): p. 20-28.
33. Neill, S., *Family Management of Acute Childhood Illness at Home: A Grounded Theory Study*, in *Nightingale School of Nursing and Midwifery*. 2008, King's College London: London.
34. Stewart, J.L. and M.H. Mishel, *Uncertainty in Childhood Illness: A Synthesis of the Parent and Child Literature.* Scholarly Inquiry for Nursing Practice, 2000. **14**(4): p. 299-319.
35. Ueki, S., et al., *Maternal Uncertainty about Infants' Hospitalization for Acute Childhood Illness: A Qualitative Study.* Open Journal of Nursing, 2017. **7**(6): p. 645-656.
36. Hugenholtz, M., C. Bröer, and R. van Daalen, *Apprehensive parents: a qualitative study of parents seeking immediate primary care for their children.* British Journal of General Practice, 2009. **59**(560): p. 173-179.

37. Jones, C., et al., *Information needs of parents for acute childhood illness: determining 'what, how, where and when' of safety netting using a qualitative exploration with parents and clinicians.* BMJ Open, 2014. **4**.
38. Jones, C.H.D., et al., *Caregivers' Experiences of Pathways to Care for Seriously Ill Children in Cape Town, South Africa: A Qualitative Investigation.* PLoS ONE, 2016. **11**(3): p. e0151606.

Appendix 1 BeArH project Gantt chart

		Pre-funding (Months)						Funded time (Months)																							Post-funded time (months)					
		Jun-17	Jul	Au	Sep	Oct	No	De	Jan-18	Feb	Ma	Apr	Ma	Jun	Jul	Au	Sep	Oct	No	De	Jan-19	Feb	Ma	Apr	Ma	Jun	Jul	Au	Sep	Oct	No	De	Jan-20	Feb	Mar	Apr	May	Jun
	Activity	1	2	3	4	5	6	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Project Management	Advisory Group meetings																																					
	Design meetings charity partners																																					
	Programme Management Team meetings																																					
	Researcher recruitment																																					
	HRA ethical and legal approvals																																					
	Site set up: KGH, LRI, NHFT, LPT, OOHSs, NHS 111, Urgent Care Centre																																					
	Update literature search/review																																					
Stage 1 documentary analysis	Source documents for review for Leicestershire & East Northamptonshire																																					
	Documentary analysis																																					
	Access and review HES data: LRI/KGH																																					
Stage 2a interview data collection	Training researchers																																					
	Family recruitment (n=20) & consent																																					
	Interviews with families																																					
	Interviews with clinicians																																					
	Data analysis																																					
Stage 2b focus group data collection	Focus groups (n=2) with parents/carers including recruitment and consent																																					
	Focus groups with clinicians (N=2) including recruitment and consent																																					
	Data analysis																																					
Data synthesis, theory development and report writing	Data synthesis																																					
	REC/HRA reports																																					
	Report writing - progress reports																																					
	Final report/open access paper writing																																					
	Dissemination of findings																																					

Appendix 2 BeArH Project approvals processes report

The process of obtaining Research Ethics Committee (REC) approval, Health Research Authority (HRA) approval, and confirmation of capacity and capability (C&C) from each participating NHS site, are completed separately, but each are interlinked and are completed in conjunction with one another. The table below outlines the dates and details of REC and HRA approval. C&C activity is further detailed in a subsequent table.

Step	Detail of HRA and REC activity	Date
1	REC application submission	7th August 2017
2	Application valid letter	21st August 2017
3	REC review meeting	12th September 2017
4	Provisional opinion from the REC	29th September 2017
5	Provisional opinion response letter submission	17th October 2017
6	HRA initial assessment letter	17th October 2017
7	Favourable opinion from the REC	8th November 2017
8	HRA approval letter	15th November 2017

Health Research Authority Research Ethics Committee approval

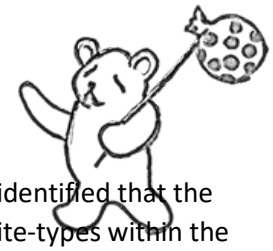
An ethics application for the project was submitted to the HRA via the Integrated Research Application System (IRAS) in August 2017 to the 'East Midlands – Nottingham 1 Research Ethics Committee' (EM-Notts 1 REC); REC reference 17/EM/0334 and IRAS ID 226756. The application was reviewed by the REC between late August 2017 and November 2017, with various amendment and/or clarifications exchanged between the REC and the study team and the REC. The REC provided the project with 'favourable opinion' on 8th November 2017.

Health Research Authority approval

Upon receiving the 'application valid' letter from the REC at the end of August 2017, this triggered the need for the HRA to begin their initial assessment of the BeArH project for HRA approval. On 17th October 2017, the research team received from the HRA their initial assessment letter for the project to confirm receipt of the application, seek clarification on elements of the application and initiate the researchers beginning the process of arranging C&C with each participating NHS site. Following the adequate response from the researchers of the clarification and amendments made from the HRA initial assessment letter, and from the receipt of HRA REC approval on 8th November 2017, the HRA provided the research team with HRA approval on 15th November 2017, following the. This letter confirmed that the BeArH project was able to commence, once confirmation of capability and capacity was obtained from each of the participating NHS organisations.

Confirmation of capacity and capability of participating NHS sites

During the process of completing the BeArH ethics application, the research team determined that the project would require support from 8 NHS organisations across Leicestershire and East Northamptonshire, in order to recruit relevant parent and health professional participants onto the study. The research team determined that all of the 8 sites would be required to support the study as a Participant Identification Centre (PICs) in order to support the recruitment of participants; all other research activities would be completed by the research team.



Although all of the 8 sites were determined to be PIC sites, the research team identified that the organisations would be undertaking different PIC activities across 4 different site-types within the study. The table below provides details of the 8 NHS sites supporting the study, what site-type each site is classed as, a breakdown of PIC research activities each site type, and dates for C&C and green lights for each site (green light means the date in which the researcher's confirmed the site can commence research activity).

NHS Site	Site type	Site type research activity					Date C&C initiated	Date C&C confirmed	Date of green light
		Stage 1	Stage 2a		Stage 2b				
			Parents	HPs	Parents	HPs			
1	1	✓	✓	✓	✓	✓	08/11/2017	21/12/2017	12/01/2018
2	1	✓	✓	✓	✓	✓	22/11/2017	24/01/2018	24/01/2018
3	2	✓		✓		✓	07/12/2017	12/12/2017	12/04/2019
4	2	✓		✓		✓	07/12/2017	06/06/2018	11/06/2019
5	2	✓	✓	✓		✓	07/12/2017	08/12/2017	03/07/2019
6	3			✓		✓	Not applicable with CRN. However communication with CRN began in October 2017.		06/03/2018
7	4			✓		✓	09/03/2018	09/04/2019	24/05/2019
8	4			✓		✓	09/03/2018	09/04/2019	24/05/2019
1. Kettering General Hospital (KGH); 2.Leicester Royal Infirmary (LRI); 3.East Midlands Ambulance Service (EMAS); 4. Leicestershire Partnership Trust (LPT); 5.Northamptonshire Healthcare NHS Foundation Trust (NHFT);6.General Practice (GP) in Leicestershire and East Northamptonshire supported through the Clinical Research Network (CRN);7.DHU Health Care (GP Out of Hours (OOHs);8.Urgent Care in Leicestershire and East Northamptonshire.									

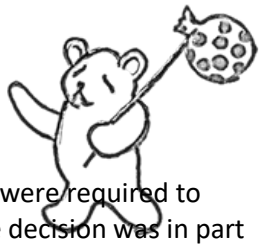
Amendments to the study

A total of 7 non-substantial amendments and 2 substantial amendments have been required for the project, following the attainment of REC favourable opinion. All amendments were approved by the HRA, and all amendments forwarded to the relevant participating NHS organisations affected by the amendment.

Amendments were required for a variety of reasons, for example changes to protocol, documentation, study team members and study timelines.

Amendment number and type	Date submitted to HRA	Date approved by HRA
Non-substantial amendment	01/12/2017	05/12/2017
Non-substantial amendment	22/12/2017	18/01/2018
Substantial amendment	27/06/2018	17/07/2018
Substantial amendment	20/08/2018	20/09/2018
Non-substantial amendment	16/02/2019	28/02/2019
Non-substantial amendment	13/03/2019	22/03/2019
Non-substantial amendment	25/06/2019	14/08/2019
Non-substantial amendment	19/07/2019	14/08/2019
Non-substantial amendment	25/08/2019	03/09/2019

Challenges related to the HRA, REC and C&C process



REC difficulty; Choosing the appropriate REC to submit to. The researcher team were required to carefully consider which local REC would be most appropriate to submit to. The decision was in part based on the submission deadlines offered by each REC, and also based on avoiding a local REC that members of the research team had submitted to for a separate research project in the past. This was because the local REC was experienced by the research team as being unnecessarily critical rather than research enabling in their approach.

REC difficulty; Inclusion and exclusion of non-English speaking participants. During the development of the ethics application and supporting documentation, the research team acknowledged the possibility of some participants being non-English speaking participants. The researchers were aware that this would be a barrier due to the lack of funds within the project to recruit a translator to support the recruitment and data collection of non-English speaking participants. These limitations were presented to the NIHR who provided agreement that due to project resource limitations, non-English speaking participants should be an exclusion criteria within the project.

REC difficulty; Inclusion of young parent participants. During the development of the ethics application and supporting documentation, the research team acknowledged the possibility of some parent participants being under the age of 16 and therefore would present additional ethical challenges due to being considered a vulnerable group. This challenge was presented to the NIHR who provided agreement that the involvement of young parents should be an inclusion criteria within the project should any young parents show an interest in engaging in the project. The research team added this into the project protocol and developed additional documentation to ethically and successfully engage with young parent populations.

HRA difficulty; Challenges in communication between the HRA and the HRA REC. During the process of obtaining ethical approval from the REC, and obtaining HRA approval (more detail provided below), the REC requirements and HRA requirements were not always complementary with one another. For example, following ethical approval of all project documentation, the HRA stipulated a number of changes were required to multiple documents in order to be compliant with HRA protocols or standards requirements. This resulted in minor details due to needing to obtain minor amendments with the REC in order to be HRA compliant.

C&C difficulty; NIHR accrual decisions. When enquiring about NIHR accruals, the majority of NHS sites expressed disappointment when informed that the NIHR stipulated that the accruals would be allocated at the time of 'consent to interview' rather than at the time of 'patient identification'. This meant that accruals would go to the University of Northampton, rather than to the sites. The university would not benefit from receiving accruals, whereas accruals are essential target indicators from the NHS sites. After discussions with the NIHR, agreements were that accruals could go to the NHS sites.

Appendix 3 Before Arrival at Hospital (BeArH) Stage 1 findings

Key messages from documentary analysis of existing evidence (stage 1)

- Higher deprivation in Leicester and the town of Corby than in the other study area areas.
- Higher children's mortality rate and higher low birth weight full term in Leicester than other study areas and above the national average for England.
- Variable pattern of health service provision
- Higher A & E attendance by 0-4 year olds in Leicestershire (excluding Leicester) than other study areas and above England average.
- The youngest children use the most hospital health care, declining year on year.
- Hospital use is higher in the winter months.
- Lack of access to CDR data so that lessons can be learnt for the future. This also means we are unable to look for the persistence of any modifiable factors in our data.

Overview

The primary aim of the documentary analysis was to map identified modifiable organizational, environmental and human factors in reports concerned with child deaths in each of the study areas, compare these data between sites in the context of patterns of service use (from HES data and EMAS data) and the services available to children, to identify patterns which can then be explored in Stage 2. The data has been presented to reflect the two study areas, Leicestershire and North Northamptonshire (North Northants), and to contextualise the two hospitals from which the families were recruited from for the stage 2a element of the study. Within this report North Northants refers to the districts of Corby, East Northamptonshire, Kettering and Wellingborough. This is not an exact division as Kettering General Hospital located in the North Northants study area, also provides services for people from South Leicestershire[1]. Also, families whose home postcode within the North Northants area may use Northamptonshire's other general hospital, Northampton General Hospital.

[1] Source Kettering General Hospital About Us https://www.kgh.nhs.uk/about-us accessed 28/04/2020

General population data

Table 1 General population data for study areas including inequality factor and wider determinants of health factor.

	Leicestershire		North Northants				England
Population Health Profile 2018/2019	**Leicester**	**Leicestershire***	**Kettering**	**Corby**	**East Northants**	**Wellingborough**	
Population figures Nos of Persons	355,218	698,268	101,266	70,827	93,906	79,478	55,977,178
% of which are children aged 0-4	7	5.3	6.1	7.2	5.4	6.3	6
% population from ethnic minorities	48.6	7.8	5.1	7.9	2.8	6.9	13.6
Inequalities							
Deprivation Score	30.9	12.3	19.2	25.7	13.9	21.7	21.8
Wider determinants of health							
% Children in low income families (under 16)	23	10.9	14.2	17.3	11.2	16.4	17
% of people in employment	66.2	79.8	73.4	77.3	82.6	73.5	75.6

Source Public Health England Local Authority Health Profiles 2019 Published 03/03/2020
https://fingertips.phe.org.uk/
*Does not include Leicester

The way the data is reported is along authority boundaries, therefore, the geographical area is reported via Leicester which is a unitary authority and Leicestershire which is a county. North Northants is constituted from four districts. The above table shows that in relation to inequality and the wider determinants of health the study areas are generally the same as or better than the national rates. This is with the exception Leicester which has a higher percentage of ethnic minorities and of children that are in low income families, and a lower percentage of people in employment than England and the overall rates for Leicestershire and the four North Northants districts.

Child population and child health data

Table 2 below shows live births, still births and still birth rates (SBR) for Leicestershire and North Northants in 2018. The way the data is reported is along authority boundaries, therefore, the geographical area is reported via Leicester which is a unitary authority and Leicestershire which is a county. North Northants is constituted from four districts. The figures below show Corby within North Northants as having the highest still birth rate, higher than the rate for England as a whole. Also, Leicestershire as having the lowest still birth rate, lower than the England rate overall.

Table 2 Child population data.

ONS 2018[2]	Leicestershire		North Northants				England
	Leicester	Leicestershire	Kettering	Corby	East Northants	Wellingborough	
Live Births	4,611	6,875	1,191	888	910	891	625,651
Still births	20	18	5	5	2	2	2,520
Still birth rate per 1,000	4.3	2.6	4.2	5.6	-	-	4.0

Child health data is reported under Leicestershire (Leicester and Leicestershire) and Northamptonshire as these reports are not available for district level data. In Table 3 below, Leicester has the highest percentage of low birth weight full term babies and is higher than the England average. Leicester also has a higher infant mortality rate than Leicestershire and Northamptonshire and is above the national average. Leicestershire has the highest 0 – 4years A & E attendances, above Leicester and Northamptonshire, and higher than the England average. Northamptonshire has lower attendance rate than the England average.

Table 3 Child health data

Child Health Profile[3]	Leicestershire		Northamptonshire	England
	Leicester	Leicestershire		
Infant mortality (per 1,000 live births) 2016/18	5.9	3.5	4.2	3.9
Child mortality rates (1-17yrs) (per 100,000 of 1-17 population)	16.4	9.7	9.6	11.0
MMR vaccination (2 year olds) 2017/18	91.5%	95.8%	91.3%	90.3%
DTaP vaccine (2 year olds) 2017/18	94.9%	97.6%	95.3%	94.2%
Low birth weight of term babies 2018	4.45%	2.50%	2.29%	2.86%
A&E attendances 0-4yrs per 1,000 0-4 population	643.9	758.5	605.7	655.3

[2] Office of National Statistics https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsummarytables

[3] Public Health England Child and Maternal Health https://fingertips.phe.org.uk/profile/child-health-profiles

Child Death Reviews

Access to child death review data was difficult and limited data was obtained. Child Death Review information regarding children who had died from infection during the two years 2015-2017 was obtained from Leicestershire, (this did not include data for Leicester). This data was very limited giving figures for number of children within the study criteria, their age, gender, the first three letters of their post code, the year they died and where they died. No further information was available, such as any learning from these events. No information was obtained from Northamptonshire or Leicester. The reason given to some degree related to concerns about confidentiality, however the main reported reason for difficulties with sharing data was capacity within the department to have the time necessary for sharing the information. This was the main reason that Northamptonshire reported for be unable to send through the information to the research team. The data we received from Leicestershire met the criteria of our study, children over 28 days and under five years old, who had had an infectious illness. From the data that was received for Leicestershire five children died, four of the children were under 1 year old, the fourth was 2 years 1 month. Of these children, four were male and one female. Three children died in the emergency department and two died in the paediatric intensive care unit. When looking at the residential postcode for these children, three lived close to the centre of Leicester (LE4 and LE5), one lived on the edge of Leicester (LE7) and one lived around the area of Loughborough (LE12). It is useful to note that the children's emergency department is within Leicester Royal Infirmary which is based in the centre of Leicester, post code LE1. It is not possible to ascertain where the child became unwell but at least three of these children had family homes close to the children's emergency department. There was no information regarding the nature of the infectious illness, for example bronchiolitis, meningitis, and therefore difficult to compare with the presentations of illness within the recruited families. These are very small numbers but when compared to recruitment information for Leicestershire. None of the recruited families in Leicestershire had children who died as a result of their illness.

The difficulties with obtaining data and how little data was available highlights the lack of information available regarding modifiable factors or learning from events and reviews.

Table 4 Child Death Review data from Leicestershire

Category	Age 1 month - 5 years	Gender	Postcode	Place of death
9. Infection	2 months	MALE	LE12	Emergency Department
9. Infection	2 years 1 month	MALE	LE4	Emergency Department
9. Infection	1 month	MALE	LE4	Paediatric Intensive Care Unit
9. Infection	4 months	MALE	LE5	Emergency Department
9. Infection	9 months	FEMALE	LE7	Paediatric Intensive Care Unit

First contact urgent care services available in study areas

Table 5 below shows first contact services in the study areas. It shows a difference of service provision between the two study areas, Leicestershire and North Northants.

Table 5 First contact urgent care services

First contact urgent care services available in study areas		
Service	**North Northants**	**Leicestershire**
Accident and Emergency Departments	Kettering General Hospital, Rothwell Rd, Kettering **NN16 8UZ**	Children's Emergency Department Leicester Royal Infirmary, Infirmary Square, Leicester **LE1 5WW**
Urgent Care Centres	Corby Urgent Care Centre Cottingham Rd, Corby **NN17 2UR**	Merlyn Vaz Walk-In Medical Centre, Spinney Hill Road, Leicester, **LE5 3GH**
		Oadby Urgent Care Centre, 18 The Parade, Oadby, **LE2 5BJ**
		Urgent Care Centre, Market Harborough District Hospital, Coventry Road, Market Harborough, **LE16 9DD**
		Urgent Care Centre, Melton Mowbray Hospital, Thorpe Road, Melton Mowbray, **LE13 1SJ**
		Urgent Care Centre, Rutland Memorial Hospital, Cold Overton Road, Oakham, **LE15 6NT**
		Urgent Care Centre, Loughborough Hospital, Hospital Way, **LE11 5YJ**

Ambulance service use data

The total number of incidents relating to children meeting the study criteria for the two years 2015/16 and 2016/17 is 632 incidents. This does not include calls to the service for children where the report stated a non-infection related reason, such as fall or injury.

Table 6 EMAS response to calls for each year of data by patient's home postcode

	Numbers by postcode			
		Leicestershire	**Northamptonshire***	**North Northants**
2015/16	N = 440	207	233	98
2016/17	N = 192	172	20	6

Of those responses to calls table 7 shows those conveyed to hospital.

		Conveyed to hospitals			
		Total conveyed	**Leicestershire**	**Northamptonshire***	**North Northants**
2015/16		376	161	215	95
2016/17		160	144	16	4

Table 7 number of children conveyed to hospital by year and area

*Figures include North Northants. One entry NN without number, unable to identify if North Northants or not.

There is a considerable difference in activity between the two years, 440 incidents 2015/16 and 192 16/17, a drop of 56%. This is in both areas, Leicestershire and Northamptonshire, but most significantly in the latter, which has a 91% drop in incidents.

Of those conveyed table 8 shows the receiving hospital by patient's home postcode and year. The column labelled North Northants is reporting hospital use where the patients post code is in North Northants. There were 10 occasions where a patient with a North Northants postcode used NGH.

Table 8 Number conveyed and the receiving hospital by patient postcode

2015/16	**Leicestershire Postcode** (N = 161)		**Northamptonshire*** (N= 215)		**North Northants** (N = 95)	
	LRI	152	KGH	85	KGH	85
			NGH	128		
	Other	9	Other	2	NGH	10
2016/17	**Leicestershire Postcode** (N = 145)		**Northamptonshire*** (N= 16)		**North Northants** (N = 4)	
	LRI	128	KGH	4	KGH	4
	Other	16**	NGH	12		

** Of these 2 were to Loughborough Urgent Care Centre

Hospital Episode Statistics data

Hospital Episode Statistics (HES) is a way of counting activity within a hospital. It is based on diagnostic classifications and records an episode of continuous care. A child may have several episodes of care during their stay in hospital and stays in hospital will not always be represented by a single HES record[4]. The numbers in these charts and tables refer to hospital episodes, and not numbers of children. Although therefore it does not give the number of children receiving treatment, it does show the level of activity and busyness of the hospital. LRI has approximately 33% more activity than KGH during 2015/16, and approximately 44% more activity than KGH in 2016/17.

Table 9 HES activity LRI and KGH 2015/16 and 2016/17

Hospital Episode Data. Children aged 28 days – 4 years													
	Apr	**May**	**June**	**July**	**Aug**	**Sept**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Totals**
2015/16													
LRI	242	245	179	180	166	243	253	384	370	305	271	252	**3,090**
KGH	154	119	126	149	105	127	205	250	233	195	211	192	**2,066**
2016/17													
LRI	227	261	262	245	177	290	319	387	298	300	228	273	**3,267**
KGH	136	172	158	185	131	149	214	289	233	190	193	205	**2,255**

Months with highest HES activity for children.

LRI: 2015/16 Nov (385), Dec (370) and Jan (305). 2016/17 Oct (319), Nov (387) and Jan (300).

KGH: 2015/16 Nov (250), Dec (233) and Feb (211).2016/17 Oct (214), Nov (289), and Dec (233).

Overall November has the most HES activity for the two years (1,311 episodes), then December (836 episodes) followed by January (605 episodes) and October (533 episodes) and February (211 episodes

Table 10. Table of LRI HES episodes by age by year 2015/16 & 2016/17

LRI HES activity by age						
Age in years	**0**	**1**	**2**	**3**	**4**	**Total**
2015/16	1049	823	520	405	293	3,090
2016/17	1099	892	523	425	328	3,267
KGH HES activity by age						
Age in years	**0**	**1**	**2**	**3**	**4**	**Total**
2015/16	763	547	300	250	206	2,066
2016/17	854	583	330	285	203	2,255

[4] Hospital Episode Statistics (HES) Analysis Guide (2015) Health and Social care Information Centre.

Appendix 4 BeArH project Publication and Dissemination Policy

Scope: This document relates to publications arising from the BeArH study, including both written and oral presentations, and to the dissemination of the study results to the participants (primary/secondary care clinicians and to parents).

Publication Policy

A number of teams and many people will contribute to the BeArH study during its course, including members of the Programme Management Group (PMG), Advisory Group (AG) members, participating clinicians, participating parents, staff from the University of Northampton, staff from the NHS, and others. This document addresses how individuals contribute to the publication process to ensure timely study outputs in an equitable, efficient and transparent manner.

Principles regarding authorship and writing

All proposals for publications using BeArH data must be approved by the PMG.

A lead author and wider writing team will be established and agreed for each identified paper.

All eligible potential contributors will have the opportunity to opt into a writing team.

It is the responsibility of the Chief Investigators (CIs) SN and SP-H to ensure balance and inclusivity in writing teams across the range of likely study publications.

It is the responsibility of the CIs, in conjunction with the lead author, to decide authorship order.

All named authors must meet authorship criteria (detailed below).

Each author should have participated sufficiently to take public responsibility for the publication's content.

A timetable for publication will be agreed with each lead author and approved by the PMG and will include a start date (for drafting) and target submission date.

Publication timetabling must account for appropriate review by the funding body (28 days notice of publication required by the NIHR RfPB).

For any one paper, each substantive new draft will be circulated by the lead author to the writing team to ensure opportunity to contribute.

If any member of a writing team does not respond to the request for input/review of the paper within an agreed time frame and also does not respond after being reminded, the lead author for the paper will remove their name.

If any eligible potential collaborator is unhappy with decisions about their involvement or non-involvement in writing any output from the BeArH project they should put their concerns in writing to the CI. The CI will raise their concerns with the PMG for discussion, the outcome of which discussion will be communicated by the CI to the complainant.

Presentations

Submission of abstracts for conference presentation should be agreed in advance with the PMG. Authors should allow sufficient time for their request to be reviewed.
If there is insufficient time for the PMG to review such a request, one of the CIs can make a decision on behalf of the team.
The body of the presentation (including posters) should be reviewed by the PMG prior to presentation. This may be completed via email.

Authorship & contributorship

The following criteria based on BMJ rules on *authorship* and *contributorship* (see http://resources.bmj.com/bmj/authors/article-submission/authorship-contributorship) will be used to acknowledge the level and nature of contribution of key individuals in publications arising from the project. Note that this states:
Authorship
The uniform requirements for manuscripts submitted to medical journals state that authorship credit should be based only on substantial contribution to:
conception and design, or analysis and interpretation of data and
drafting the article or revising it critically for important intellectual content and
final approval of the version to be published.

All these conditions must be met. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

The lead author and/or one of the CIs will be identified as guarantors of the paper. The guarantor accepts full responsibility for the work and/or the conduct of the study, had access to the data, and has controlled the decision to publish.

Publication level & authorship listing

Publications fall into two categories which will be agreed by the PMG:

Level 1 - Publications central to BeArH study
Authorship will take the form 'A, B, C … and the BeArH study team'. Members of the PMG would usually be able to list such publications in their CVs.

Level 2 - Publications derived from BeArH study, but not central to it
Authorship will take the form 'A, B, C … in collaboration with the BeArH study team'. In normal circumstances other members of the PMG would not list such publications in their CVs.

Level 3 - Publications derived from BeArH study, but requiring additional funding to complete
Authorship will take the form 'A, B, C … in collaboration with the BeArH study team'. In normal circumstances other members of the PMG would not list such publications in their CVs.

Contributorship and acknowledgements

Contributors to the BeArH study will be acknowledged on each publication and, once available, on the study website. Where journal restrictions apply, it may be that readers are simply directed to the study website for full details of contribution. Contributorship relates to the BeArH study as a whole, not necessarily individual study outputs. Contributors may also be already listed as authors on individual papers. Two levels of contributorship are distinguished:

i) Major contributor (named author)

Members of the PMG who have made a major *scientific* contribution to design, data collection, analysis or reporting, over a period of at least six months. Whilst it is likely that an individual's contribution will be continuous, for some it may have been appropriately intermittent. They should have devoted a modicum of their employed time to the study during each month of that period. Acknowledgement as a major contributor is reserved for those people who have invested heavily in the study.

ii) Other contributors (organisational, clinical or administrative)

These should have made a minor scientific or major non-scientific contribution to implementing the protocol over a period of at least six months e.g. administrative staff, research nurses, clinical collaborators, charity representative and PPI collaborators.

Constructing the contributorship statement

The following criteria are suggested for classifying contribution to study output:

Co-CIs and guarantors of the study in its entirety (i.e. SN, SP-H)
Developing research question & study design (likely to be most of the co-applicants and key collaborators)
Implementation of the study protocol (likely to be all PMG members, and other key individuals)
Study management (e.g. NB)
Writing the manuscript (core writing team for the paper)
Reading, commenting upon, & approving final manuscript (all those who appear as named authors)

The contributorship statement would then present this information in narrative format. An example statement would be:

'SN was CI and guarantor of the study in its entirety. Xxxxx etc. were responsible for developing the research question and study design …'

The contributorship statement would be drafted by the lead writer (in conjunction with SN) and circulated as part of the draft manuscript for endorsement / modification by the other authors.

Acknowledgements

We shall acknowledge all others who have played a part in the study but do not fulfil the criteria for contributors.

All output should acknowledge the study funders and carry the appropriate disclaimer. The funding body must be notified about all study output in accordance with the primary study contract.

Access to/use of study data

Any use of study data, including process and outcome data, beyond the study team must be subject to prior approval from the PMG, which must include both CIs.

Such requests must be in writing and clearly describe the purpose for which the data is required and how it is to be used.

All output from such work must acknowledge the source of the data, and its use must be consistent with ethical and governance approval, (either existing or subsequently sought).

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LB	Lucy Bray
LR	Lucie Riches
NB	Natasha Bayes
SN	Sarah Neill
SPH	Sue Palmer-Hill

Table of planned publications – authorship is subject to ongoing study activity

Publication planned	**Type**	**Proposed site(s) for publication**	**Proposed Authorship. Lead in bold.**
Before Arrival at Hospital: Factors affecting timing of admission to hospital for children with serious infectious illness (The BeArH project) final report to the RfPB	Research report	NIHR RfPB	**SN,** KWD, NB, LB, BC, DR and the BeArH study team.
Getting The Whole Picture: Designing Studies To Capture 360 Degree Data On Family Health Service Use.	Methods paper	TBC	**KWD,** SN, BC & the BeArH study team.
Dissonance between what is found in the real world and the narratives around tragedies.	Editorial	TBC	**DR,** in collaboration with the BeArH study team
Barriers to recruitment created by ethical approval processes.	Methods paper	TBC	BC & NB and the BeArH study team.
Uncertain illness trajectories: parents' experiences of seeking help for a child with a serious infectious illness	Research report	TBC	**SN**, LB and the BeArH study team.
Young children's uncertain illness trajectories – professionals' experiences of risk and uncertainty	Research report	TBC	**SN**, LB, DR and the BeArH study team.
Complex health services for the sick child: impact on timely treatment for serious infectious illness	Research report	TBC	**SN**, LB and the BeArH study team.
A systematic review of the organizational, environmental, professional and child and	Literature review	Submitted to PLOSONE April 2020	**BC**, DR, LB, JHa, PP, JF, EC and SN.

family factors influencing the timing of admission to hospital for children with serious infectious illness.			
An exploration of the fragmentation of healthcare	Editorial	TBC	**SPH,** SN, KWD
Technology used by parents	Editorial	TBC	**KWD** and the BeArH study team
Working together: the value of embedding PPI in parent research.	Methods paper	TBC	**BC**, LR, JH, SN

Written output: milestones for main writing activity / submission dates (during funded timescale of study)

Written output	Authors	Submission dates	Status
Progress report 1	TB, KWD, SN	15th June 2018	Submitted
Progress report 2	TB, KWD, SPH, SN	17th December 20	Submitted
Final report	SN, TB, KWD, BC, LB, DR, EC, JHu, LR, JOD, SPH	17th June 2020	Extension secured to 17th June 2020 (original date was 18th December 2019)

General model for paper writing in BeArH Study

Development stage	Paper flow	Timeline
	Lead author	
First substantive draft, in consultation with authoring team	↓	Timescale agreed with CIs. (Suggested ideal timings below.)
	Authoring team [1] ← ⋯	4 weeks (4+ if further iterations required)
Formal review of ***first*** draft	↓	
	Lead author ⋯	
Revision based on feedback	↓	2 weeks
	Programme Management Group[2]	
Formal review of ***second*** draft	↓	3 weeks
	Lead author	
Revision based on feedback, ***finalise*** manuscript	↓	2 weeks
	Submission	

1 Identified as named authors on final submission
2 Identified as the BeArH Study Team on final submission

Conferences – actual presentations

	Status	Date of conference	Conference	Venue	Title	Presenter	Type
1	Delivered	21st June 2019	UoN Graduate School Conference	University of Northampton	Getting The Whole Picture: Designing Studies To Capture 360 Degree Data On Family Health Service Use.	Kim Woodbridge-Dodd and Sarah Neill	Concurrent
2	Delivered	14-16th August 2019	14th International Family Nursing Conference	Washington DC	Getting The Whole Picture: Designing Studies To Capture 360 Degree Data On Family Health Service Use.	Sarah Neill	Concurrent
3							
4							
5							
6							
7							
8							

Proposed conferences

	Status	Date of conference	Conference	Venue	Title	Presenter	Type

Dissemination to secondary care sites, NHS staff, patients/parents (proposal) - TBC

BeArH FINDINGS: OPTIONS FOR DISSEMINATION							
Audience	**Content**	**Format**	**Timing**	**Justification**	**Cost**	**Lead**	**Status**
General public	Key findings from the project	News article for The Conversation	Following publication of the report	Disseminating findings to wider audience	None	SN & BC	
	Key finding and link to report	Social media	Following publication of the report	Disseminating findings to wider audience	None	All team members	
Staff on both study sites and in related first contact services	Key findings from the project	Presentation – may be virtual	Post pandemic	Feedback of findings to health professionals on each participating site	TBC depending on mode of delivery	PIs for each site and CI	
Participants who have requested a summary of findings	Summary of the project and its findings	Plain English Summary	Following publication of the report	Participants requested a summary of findings		NB	
Charity partners	Study report	Posts for charities websites and social media sites	Following publication of the report	Dissemination of findings to charity audiences	None	Charity partners	

Table 1 Parent interview participant characteristics (N=23~)

Characteristic	Number of parents (%)
Age	
25-29 years	3 (13%)
30-39 years	10 (44%)
40-49 years	0
50-59 years	1 (4%)
60+ years	3 (13%)
Gender	
Female	12 (52%)
Male	9 (39%)
Ethnicity	
White British	12 (52%)
Indian	6 (26%)
Employment	
Employed (part or full time)	8 (35%)
Unemployed or retired	3 (13%)
Caring for family at home	5 (22%)
Age of affected child*	
Under 6 months	1 (8%)
6-12 months	2 (17%)
13-23 months	2 (17%)
2 years old	3 (25%)
3 years old	2 (17%)
4 years old	2 (17%)

Characteristic	Number of parents (%)
Relationship to the child	
Parent: Mother	10 (44%)
Parent: Father	7 (30%)
Grandparent (maternal; paternal; in law)	3 (13%)
Aunt/Uncle	2 (9%)
Neighbour	1 (4%)
Income	
Less than 10,000	3 (13%)
10,000-19,999	5 (22%)
20,000-29,999	4 (17%)
30,000-39,999	5 (22%)
40,000-49,999	0
50,000-59,999	2 (9%)
60,000-79,999	2 (9%)
80,000-99,999	1 (4%)
100,000+	3 (13%)
Diagnoses of affected child*&**	
Acute Respiratory	12 (52%)
Acute exacerbation of recurrent respiratory	5 (22%)
Acute disseminated encephalomyelitis (ADEM)	1 (4%)
Tonsillitis	1 (4%)
Sepsis and Septicaemia	2 (9%)

~Although 23 parents 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 this phase, not on the total number of parents (N=23) engaged in this phase.**

****Many children had multiple diagnoses.**

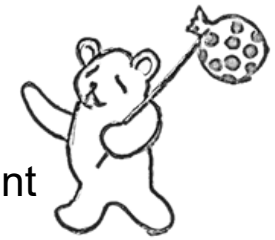


Table 2 Health professional (HP) interview participant characteristics (N=14~)

Characteristic	Number of HPs (%)
Age	
21-29 years	5 (36%)
30-39 years	5 (36%)
40-49 years	1 (7%)
50-59 years	3 (21%)
Gender	
Female	9 (64%)
Male	4 (29%)
Ethnicity	
White British	11 (79%)
Indian	1 (7%)
Other*	2 (14%)
Employment	
Employed (full time)	14 (100%)

Characteristic	Number of HPs (%)
Service type**	
Ambulance Service	6 (43%),
Emergency Care	8 (57%)
Other***	2 (14%)
Job title	
Emergency Medical Technician	3 (21%)
Emergency Medical Dispatcher	1 (7%)
Emergency Medical Consultant	1 (7%)
Emergency Care Assistant	1 (7%)
Emergency Care Nurse	2 (14%)
Junior Doctor	1 (7%)
Paramedic	3 (21%)
Health Advisor	2 (14%)

~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

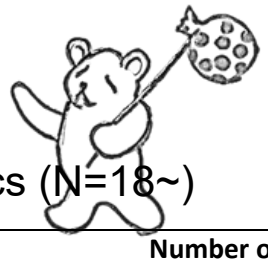


Table 3 Parent focus group participant characteristics (N=18~)

Characteristic	Number of parents (%)
Age	
30-39 years	11 (61%)
40-49 years	5 (28%)
Gender	
Female	14 (78%)
Male	2 (11%)
Ethnicity	
White British	12 (67%)
White other*	3 (17%)
Employment Status	
Employed (part or full time)	12 (67%)
Unemployed	1 (6%)
Caring for family at home	3 (17%)
Age of affected child**	
Under 6 months	6 (38%)
6-12 months	4 (25%)
13-23 months	2 (13%)
2 years old	0
3 years old	2 (13%)
4 years old	2 (13%)

Characteristic	Number of parents (%)
Relationship to the child	
Parent: Mother	15 (83%),
Parent: Father	2 (11%)
Income	
Less than 10,000	2 (11%)
10,000-19,999	3 (17%)
20,000-29,999	0
30,000-39,999	0
40,000-49,999	1 (6%)
50,000-59,999	1 (6%)
60,000-79,999	3 (17%)
80,000-99,999	4 (22%)
100,000+	2 (17%)
Diagnoses of affected child&*****	
Acute Respiratory	1 (6%)
Sepsis and Septicaemia	6 (38%)
Meningitis	14 (88%)

~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 this phase, not on the total number of parents (N=18) engaged in this phase.**

*****Many children have multiple diagnoses.**

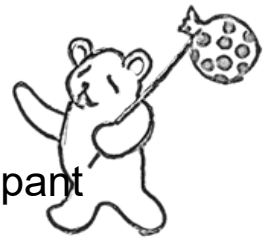


Table 4 Health professional (HP) focus group participant characteristics (N=16~)

Characteristic	Number of HPs (%)
Age	
21-29 years	2 (13%)
30-39 years	6 (38%)
40-49 years	4 (25%)
50-59 years	4 (25%)
Gender	
Female	9 (56%)
Male	5 (32%)
Ethnicity	
White British	10 (63%)
South Asian*	3 (19%)
African	1 (6%)
Other*	2 (13%)
Employment	
Employed (full time)	12 (75%)
Employed (part time)	4 (25%)

Characteristic	Number of HPs (%)
Service type	
General Practice	5 (32%)
Emergency Care	5 (32%)
Ambulance Service	2 (13%)
Other**	4 (25%)
Job title	
General Practitioner	5 (32%)
Paediatric Emergency Medical Consultant	4 (25%)
Emergency Care Children's Nurse	1 (6%)
Community Children's Nurse	1 (6%)
Paramedic	2 (13%)
Other***	3 (19%)

~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**

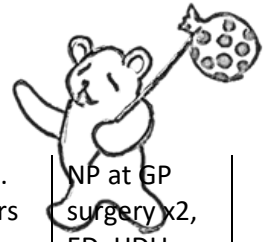
**** NHS111, Community**

*****Community Pharmacist, Dental Hygienist Oral Health Lead, Health Advisor**

Table 5 Stage 2a parent/carer participant and child characteristics

TH Teaching hospital DGH District general hospital

Stage 2a Case	Family members interviewed	Age and gender of affected child	Household composition	Ethnic group	Pre-existing conditions	Diagnosis for this illness	Duration of this illness prior to admission	Services accessed pre-hospital and admitting unit
THP004	Mum	14 month old girl born pre-term at 25 weeks	Two parents No siblings	White British	Chronic lung disease	?Bronchiolitis	3 + days	GP, CAU, Ambulance, ED, HDU
THP005	Dad	5 week old first born boy	Two parents in extended family household of 8 adults and 4 children	Unknown	Unknown	RSV Bronchiolitis and Influenza A	Approx. 7 days	GP x3, EDx2, CAU, PICU
THP008	Mum and Dad	4 year old boy	Two parents, paternal grandfather and 2 year old sister.	Indian	Krabbe disease with developmental delay Previous hospital admissions ++	?Chest infection	Approx. 6 days	GP, Ambulance, ED, PICU
THP010	Mum and Dad	3 year old girl	Two parents and 10 month old sibling.	White British	Asthma (Dad also has asthma)	?Asthma attack and chest infection	1.5 days	NP at GP surgery, Ambulance, ED, PICU



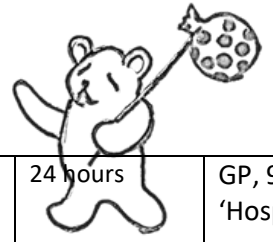
THP012	Mum	2 year old boy	Two parents and 7 & 10 year old siblings.	Indian	Asthma Previous hospital admissions but not to HDU	Asthma attack and chest infection	Approx. 12 hours	NP at GP surgery x2, ED, HDU
THP018	Mum, Parent's in law	2 year old girl	Two parents, 3 month and 5 year old siblings. Grandparents live nearby.	Indian	None	*'Chest infection and later pneumonia, fluid around the lung and Strep A blood infection'*	2.5 days	NHS 111, Ambulance, ED, HDU/PICU
THP021	Mum, Dad and Neighbour (to translate)	2 year old girl	Two parents and siblings aged 6 and 13 years.	Indian	No information	ADEM - Acute disseminated encephalomyelitis	6 days	GP x2, ED x2, Walk-in Centre, ED, HDU/PICU
THP022	Great Aunt and Uncle	4 year old girl	Great aunt and uncle (Gran and Papa in the account).	White British	Bilateral cystic periventricular leukomalacia, quadriplegic cerebral palsy, registered blind, ventricular septal defect, epilepsy, global developmental delay. Previous hospital admissions.	Tonsillitis with obstruction	7 days	Walk-in Centre, locum GP, NHS 111, Ambulance, ED, PICU

THP027	Mum and Maternal Grandmother	6 month old boy, born pre-term at 35 weeks.	Two parents and 2 year old sibling.	White British	Laryngo-malacia and reflux. '*Currently being diagnosed'* Previous hospital admissions ++ Grandmother reported multiple ear infections.	Bronchiolitis (recurrence) with obstruction	10 days	Resuscitated by Mum, Ambulance, ED, PICU
DGHP001	Mum and Dad	17 month old boy	Two parents. No siblings.	White British	None	Collapsed lung and sepsis	12 days	GP x3, NHS 111, ED, HDU
DGHP002	Mum and Dad	6 month old	Two parents and 2 year old sibling.	White British	None	Partially collapsed lung secondary to ?chest infection/pneumonia	Approx. 8 days	GP x2, NHS 111, Ambulance, ED, HDU
DGHP003	Mum and Dad	3 year old boy	Two parents. No siblings.	White British	None	Pneumonia	7 days	GP, NHS 111, Ambulance, 999, ED, HDU/PICU

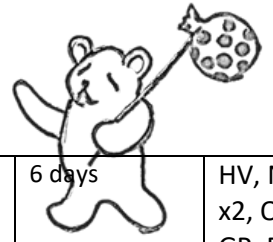
Table 6 Stage 2b parent demographic characteristics

MID1PFG = Parent Focus group 1: Midlands 1, August 2019 MID2PFG = Parent Focus group 2: Midlands 2, October 2019
LONPFG = Parent Focus group 3, London, October 2019 PFGT =Parent Focus group alternative telephone interview, October 2019
PFGE = Parent focus group alternative email interview, October 2019
M = Mum D=Dad followed by the number of the participant e.g. M1

Stage 2b Case	Family members interviewed	Age and gender of affected child	Household composition	Ethnic group	Pre-existing conditions	Diagnosis for this illness	Sequelae of the illness	Duration of this illness prior to admission	Services accessed pre-hospital and admitting unit
MID1PFGM1	Mum	9 month old girl	Two parents and two children.	White British	Global development delay	Bronchiolitis	Unknown	Not known	ED, HDU
MID1PFGM2	Mum	8 month old boy	One parent and four children.	White British	None	Meningitis and sepsis	Right below elbow amputee. Acquired brain injury. Stomach damage causing food sensitivities. Growth plate damage	4 days	NHS111, Ambulance, ED, Ward
MID2PFGM1	Mum	4 year old boy	Two parents and six children.	White British		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'
MID2PFGM2	Mum	10 month old girl	Two parents and three children.	White British		Meningococcal septicaemia	Unknown	24 hours	GP, ED, PICU



MID2PFGM3 &D4	Mum and Dad	6 week old girl	Two parents and two children.	White British		Late onset group B streptococcus meningitis	Child died	24 hours	GP, 999, ED, 'Hospital'
MID2PFGM5 &D6	Mum and Dad	3 year old girl	Two parents and two children.	White British		Meningitis B	Child died	< 24 hours	999, ED, PICU
MID2PFGM7	Mum	4 year old boy	Two parents and one child.	White British		Meningitis	Child died	3 days	ED, 'Hospital'
LONPFGM1	Mum	3 year old girl	Two parents and two children.	White British		Meningococcal disease	Unknown	24 hours	GP, NHS111, Ambulance, ED, PICU
LONPFGM2	Mum	1 year old girl			Repeated ear infections.	Pneumococcal meningitis	Child died	2 weeks +	GPx4, ED, Adult HDU
LONPFGM3	Mum	8 month old boy	Two parents and two children.	White British		Pneumococcal meningitis	Unknown	2 weeks +	Walk-in centre, GP, ED, 'Hospital'
PFGTM1	Mum	18 month old girl				Bacterial meningitis and septicaemia	Unknown	2 days	OOHS GP, EDx2, 'Hospital'
PFGTM2	Mum	4 week old girl	Two parents and two children.	White British		Viral meningitis	Unknown	12 hours	NHS24, OOHS Nurse, Ambulance, ED, 'Hospital'
PFGTM3	Mum	10 week old boy	Two parents and one child.	Irish		Meningitis	Unknown	12 hours	GP, ED, 'Hospital'
PFGTM4	Mum	4.5 week old boy	Three adults and one child	White British		Meningitis and sepsis	Unknown	<24 hours	NHS111, Urgent Care Centre, 'Hospital'



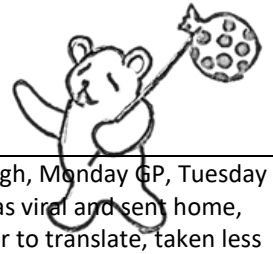
PFGEM1	Mum	7 week old girl	Two adults and four children.	White Scottish		Urinary sepsis	Unknown	6 days	HV, NHS24 x2, OOHS GP, GP, ED, 'Hospital'
PFGEM2	Mum	4 month old boy	Two adults and three children.	White European		Meningitis and septicaemia	Growth plates affected result in leg length discrepancy	<24 hours	GP, GP OOHS, Cottage Hospital, Ambulance, PICU

N.B. 'Hospital' is given as the admitting unit where not information was provided about the unit to which the child was admitted.

Table 7 Stage 2a Illness trajectories

TH Teaching hospital DGH District general hospital

Family identifier	Age/Sex of child	Duration of this illness pre-admission	Diagnosis for this illness	Illness trajectory
THP004	14 month old girl	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
THP005	5 week old boy	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).
THP008*	4 year old boy	Approx. 6 days	?Chest infection	Friday completed course of antibiotics, Mum away from home post surgery so cared for by Dad (first time on his own), well until Sunday morning, Dad detected high temp. gave Calprofen, called Mum, Mum visited Sunday evening, holds him, he is floppy, going grey around eyes and mouth, called ambulance Sunday evening, admitted to PICU.
THP010	3 year old girl	1.5 days	?Asthma attack and chest infection	Monday first ill, coughing and wheezing throughout the night, given inhalers, Mum didn't want to wake Dad so waited for surgery to open next day, Tuesday saw GP nurse practitioner who gave nebuliser, called ambulance, admitted to PICU.
THP012	2 year old boy	Approx. 12 hours	Asthma attack and chest infection	Thursday morning high temp and slight wheeze, saw GP nurse practitioner 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 Dad to come back from work, then to pack bags including food for Mum as it was Ramadan, picked up other children from after school club, taken to ED that evening by car, admitted to HDU
THP018	2 year old girl	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 Mum could Christmas shop, no bounce back on paracetamol, had wet herself when she woke, Grandmother advised seeking GP, Mum said she had but didn't, Dad went to work Christmas party &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



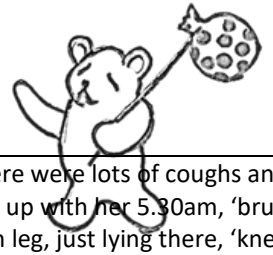
THP021	2 year old girl	6 days	ADEM - Acute disseminated encephalomyelitis	Language difficulties. Sunday first ill with D&V and temp a bit high, Monday GP, Tuesday GP, told it was flu', Wednesday ED with Dad 6-7 hours told it was viral and sent home, getting worse & nose bleed, Thursday ED with teenage daughter to translate, taken less seriously than when Dad 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.
THP022*	4 year old girl	7 days	Tonsillitis with obstruction	Sunday cough, temperature responsive to paracetamol, walk-in centre red throat & 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
THP027*	6 month old boy	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 Mum went to his room to find him really distressed, he gasped and stopped breathing. 1am Monday morning resuscitated at home by Mum, called ambulance, ED, PICU.
DGHP001"	17 month old boy	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 & given antibiotics, felt reassured, Mum sent Dad 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
DGHP002	6 month old girl	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
DGHP003	3 year old boy	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

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

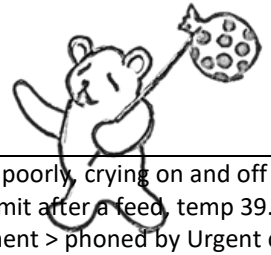
Table 8 Stage 2b illness trajectories

MID1PFG = Parent Focus group 1: Midlands 1, August 2019 MID2PFG = Parent Focus group 2: Midlands 2, October 2019
LONPFG = Parent Focus group 3, London, October 2019 PFGT = Parent Focus group alternative telephone interview, October 2019
PFGE = Parent focus group alternative email interview, October 2019
M = Mum D=Dad followed by the number of the participant e.g. M1

Stage 2b Case	**Age/Sex of child**	**Duration of this illness pre-admission**	**Diagnosis for this illness**	**Number of contacts with health services**	**Help seeking trajectory**
MID1PFGM1	girl	Not known	Bronchiolitis	1	Previous experience of NHS 111 sending ambulance when it was not warranted put them off calling them and delayed help seeking. Mother's Day, Mum out with friends, Dad phoned to say breathing really bad, instructed Dad to give inhaler, Mum came home and saw she was gasping for breath > to ED in their car > Adult resusc > Paediatric HDU
MID1PFGM2	8 month old boy	4 days	Meningitis and sepsis	3	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 Mum refused to leave, Mum 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.
MID2PFGM1	4 year old boy	3 days	Meningitis	3	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.
MID2PFGM2	10 month old girl	24 hours	Meningococcal septicaemia	2	Woke crying, high temp., came down in response to paracetamol, diarrhoea, slept with Mum, woke in the morning with funny breathing, very still > rang GP, no urgent appointments >took child to GP demanding to be see > GP told them to go straight to ED > PICU
MID2PFGM3&D4	6 week old girl	24 hours	Late onset group B streptococcus meningitis	3	Had a cold > GP as not 'quite herself', Mum worked there and GP trusted her judgement & didn't examine her > early hours of the morning Mum 'jolted awake' as she hadn't woken for a feed, floppy > rang 999 > hospital > ***died***



MID2PFGM5&D6	3 year old girl	< 24 hours	Meningitis B	2	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
MID2PFGM7	4 year old boy	3 days	Meningitis	1	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.
LONPFGM1	3 year old girl	24 hours	Meningococcal disease	4	Nursery Mon am, pm sofa day, then vomiting, rang GP – 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
LONPFGM2	1 year old girl	2 weeks +	Pneumococcal meningitis	5	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 > ***died***.
LONPFGM3	8 month old boy	2 weeks +	Pneumococcal meningitis	3	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 'nothing that sinister' but Mum asked if he should go to ED, GP response 'I guess' > ED, deteriorated within an hour > in hospital for 10 days.
PFGTM1	18 month old girl	2 days	Bacterial meningitis and septicaemia	3	Weekend. Woke in the night on Friday, vomited, high temp.. A bit unwell Saturday had a couple of spots > glass test, 'kind of disappeared', temp 39.7 > rang OOHS GP > saw GP almost immediately, temp over 40 >referred to hospital >discharged, told 'it's probably just chickenpox', 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.
PFGTM2	4 week old girl	12 hours	Viral meningitis	4	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. Mum had no idea that it was serious.
PFGTM3	10 week old boy	12 hours	Meningitis	2	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 > Nanny drove them instead. Had a 'small rash', blanched with glass test. Didn't want to waste NHS time in an overburdened system.



PFGTM4	4 ½ week old boy	<24 hours	Meningitis and sepsis	2	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.
PFGEM1	7 week old girl	6 days	Urinary sepsis	6	Initially snuffly on Wednesday/Thursday, Friday saw HV who noted she was unwell but not concerned, 11pm woke with temperature > Called NHS 24, 'just a cold' > 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 'she looks like she is dead', almost grey, temp 41 > GP > hospital. NB Delayed help seeking after Saturday consultation due to criticism, false reassurance 'It's just a cold'.
PFGEM2	4 month old boy	<24 hours	Meningitis and septicaemia	4	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'

Table 9 Stage 2a Children's help seeking on their illness trajectory to hospital admission

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

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

Stage 2a Case	Duration of illness	Social network	Primary care	Urgent care / walk-in centre	NHS 111	OOHS	999/ Ambulance	A&E/CAU	Number of pre-admission contacts with health services
THP004	3 + days		●				●	● ●	4
THP005	Approx. 7 days	●	● ● ●					● ● ●	6
THP008	Approx. 6 days		●				●	●	3
THP010	1.5 days		●				●	●	3
THP012	Approx. 12 hours		● ●					●	3
THP018	2.5 days	●			●		●	●	3
THP021	6 days	● ●	● ●	●				● ● ●	6
THP022	7 days		●	●	●		●	●	5
THP027	10 days						●	●	2
DGHP001	12 days		● ● ●		●			●	5
DGHP002	Approx. 8 days	●	● ●		●		●	●	5
DGHP003	7 days		●		●		● ●	●	5

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

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

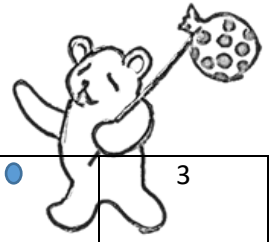
Parent Focus group 1: Midlands 1 (MID1PFG), August 2019 Parent Focus group 2: Midlands 2 (MID2PFG), October 2019

Parent Focus group 3, London (LONPFG), October 2019 Parent Focus group alternative telephone interview (PFGT): October 2019

Parent focus group alternative email interview (PFGE): October 2019

M = Mum D=Dad followed by the number of the participant e.g. M1

Stage 2b Case	Duration of illness	Social network	Primary care	Urgent care / walk-in centre	NHS 111/ NHS24	OOHS	999/ Ambulance	A&E/CAU	Number of pre-admission contacts with health services
MID1PFGM1	Not in the data	●						●	1
MID1PFGM2	4 days				●			●	3
MID2PFGM1	3 days		●				●	●	3
MID2PFGM2	24 hours		●					●	2
MID2PFGM3&D4	24 hours		●				●	●	3
MID2PFGM5&D6	< 24 hours						●	●	2
MID2PFGM7	3 days	●						●	1
LONPFGM1	24 hours				●		●	●	3
LONPFGM2	2 weeks +		●					●	2



LONPFGM3	2 weeks +		●	●				●	3
PFGTM1	2 days					●		● ●	3
PFGTM2	12 hours				●	●	●	●	4
PFGTM3	12 hours	●	●					●	2
PFGTM4	<24 hours			●	●				2
PFGEM1	6 days		● ●		● ●	●		●	6
PFGEM2	<24 hours		●			●	●		3