

To understand and improve  
the experience of parents  
and carers who need advice  
when a child has a fever  
(high temperature)

Funded and Commissioned by  
Department of Health

## RESEARCH REPORT

March 2010

Royal College of Paediatrics and Child Health  
Royal College of General Practitioners  
College of Emergency Medicine  
NHS Direct  
Joint Royal Colleges Ambulance Liaison  
Committee  
University of Leicester  
University of Nottingham



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Royal College of Paediatrics and Child Health  
Science and Research Department

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## Project Group Membership

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Dr Venkat Reddy, NHS Institute for Innovation and Improvement.

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## Glossary

<i>Antipyretics</i>	The definition is taken from the NICE guideline for Feverish Illness <sup>1</sup> : “Procedures or medications used with the intent of reducing body temperature in patients with fever. The term includes physical cooling methods and antipyretic medication. Paracetamol and ibuprofen are the drugs commonly used for this purpose in the UK.”
<i>Children's Assessment Unit (CAU)</i>	Urgent specialist paediatric assessment / admission unit or ward based at the hospital.
<i>Contact</i>	Any contact with a service whether face to face or by telephone. A parent's call to NHS Direct and a call-back from an NHS Direct professional is counted as one contact.
<i>Febrile convulsions</i>	Fits or seizures caused by a very high body temperature in children.
<i>Remote assessment</i>	An assessment conducted by telephone.
<i>Safety netting</i>	The definition is taken from the NICE guideline for Feverish Illness <sup>1</sup> : “The provision of support for patients in whom the clinician has some uncertainty as to whether the patient has a self-limiting illness and is concerned that their condition may deteriorate. Safety netting may take a number of forms, such as dialogue with the patient or carer about symptoms and signs to watch for, advice about when to seek further medical attention, review after a set period, and liaising with other healthcare services.”
<i>Self-limiting illness</i>	An illness that terminates by the natural course of events.
<i>Urgent Care</i>	The definition of “urgent care” used in this study is taken from <i>Making It Better: For Children and Young People</i> <sup>2</sup> : “the range of responses that health and care services provide to people who require – or perceive the need for – urgent advice, care, treatment or diagnosis.”
<i>Walk-in Centre</i>	In this report, a Walk-in Centre refers to any primary care service (staffed by GPs or other autonomous practitioners) that provides unscheduled care on a drop in basis.

## Foreword

This ambitious project involved joint working from health professionals in different settings studying the patient pathway for children with feverish illness. The outcomes from this study underline the essential role of general practice in provision of urgent care for children. Parents would rather see their GP when their child becomes unwell with a fever than use other services. When GPs assess children, the majority have no or one further referral. Parents were satisfied with access to their practice, but also knew and used the range of services available locally. However, where parents had several contacts with health professionals during the same illness episode this was usually because of referrals between services rather than parent initiated and inevitably was found by families to be time consuming, disruptive and stressful.

Implementation of the fever management traffic light system in the NICE Feverish Illness in Children Guideline was disappointingly low in some settings and parents were generally unaware of its existence.

Parents were clear they wished their concerns to be listened to and not dismissed. Parents were also clear about their need to have access to straight-forward and consistent advice on how to assess illness in their child, the treatment options available, how to use medicines safely and what should prompt them to return to the doctor.

There is plenty of room to improve the provision of urgent care for children, so that families are better informed how to assess and manage childhood illness and when to seek further help from health services. General practice is a key access point that leads to an efficient patient pathway. It is clearly important that members of clinical staff working in this and any other setting are trained and develop expertise in recognising and managing ill children, give clear and appropriate safety net advice and help parents understand the likely course of their child's illness.

I am confident that the new evidence based, internet accessible training aid in recognising serious illness in children, *Spotting the Sick Child*, <https://www.spottingthesickchild.com/> will help all health care staff who may contribute to the assessment of sick children. I believe the newly revised and updated Department of Health publications, *Birth to Five*, copies of which go to every family, will contribute to the information parents need. However, there is more to do in this area of information for families.

We need to deliver as well as describe optimum evidence based pathways for ill children and I welcome this work as an important and valuable contribution to this ambition.



Sheila Shribman

National Clinical Director for Children, Young People and Maternity Services

# Executive Summary

## Background

Children and young people are frequent users of urgent care services.<sup>3,4,5</sup> During the consultation on the Department of Health, *Direction of Travel for Urgent Care: A discussion document*<sup>6</sup>, concerns were expressed that the needs of children and young people were not being met. In 2008, the Department of Health commissioned the Royal College of Paediatrics and Child Health to conduct an exploratory study into this area, using the NICE guideline, *Feverish Illness in Children: Assessment and Initial management of children younger than 5 years*<sup>1</sup> as a framework. The study objectives were:

1. To define the current pattern of care for children aged less than five years presenting to primary, secondary or non face to face care with feverish illness.
2. To understand how parents navigate the urgent healthcare service options available to them and their views of that experience.
3. To determine whether urgent care services are triaging acutely ill (febrile) children appropriately, using the current NICE guideline for Feverish Illness as a framework.
4. To feed back findings to commissioners and providers of urgent care services and to produce recommendations for best practice.

The study was jointly undertaken by a consortium which was led by Royal College of Paediatrics and Child Health and included representatives of the Royal College of General Practitioners, College of Emergency Medicine, Joint Royal Colleges Ambulance Liaison Committee, NHS Direct and academic departments of the Universities of Leicester and Nottingham.

## Method

Parents using any urgent care service (GP, Walk-in Centre, Out of Hours GP, Children's Admissions Unit (CAU), Emergency Department (ED), 'other'\* primary care services, Ambulance, NHS Direct) within Leicestershire (County and City), Peterborough, and North West London for a febrile child less than 5 years during the period January to June 2009 were approached. Data was collected via a parent telephone questionnaire, parent telephone interview and the clinical notes. Workshops were held with health professionals in each local area to feedback findings.

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\*'Other' primary care services refer to any community based health professional and includes pharmacists, midwives, health visitors. It includes a unit of community paediatric specialist nurses who visit acutely unwell children at home to assess their condition and offer advice and support to parents until the children are better. This service is unique to one region

## Key findings

- Of 556 parents expressing an interest, 220 enrolled, making 570 contacts (median 3, range 1-13) across all services during this illness, despite the child's episode of illness lasting only three days on average. Approximately half of repeat contacts (221 of 350) were initiated by the services themselves, rather than by parents.
- Parents understood local urgent care options, and their preference for initial advice if in hours was their GP (67%) and when they were unavailable, NHS Direct (46%).
- A pattern of 'doctor-shopping' was not apparent in the data. Reasons for using particular services included convenience, perceived severity of the child's illness, need for reassurance and availability of GP.
- Fifteen (3%) of the 570 contacts were calls to the ambulance service of which nine were for children with a febrile convulsion. Most parents perceived their child to be very sick (high risk - see Appendix 1 for definition) at the time (69%). Unfortunately, no data was collected by the ambulance services in relation to 'stay at home' decisions; the ambulance data was restricted to those who were transported to secondary care.
- Secondary care services (CAU or ED) were used on 148 out of 570 occasions at any point during the journey; 40 were high risk according to the parent compared to 7 according to the health professional. Of the 83 attendances to EDs, 40 were a result of a referral by another service.
- 81% of parents recalled receiving safety netting advice (i.e. told what to do if their child got worse / there was a change / didn't get better). Parents who did not receive safety netting advice were more likely to seek another contact than those who did (52% vs. 35%;  $p=0.01$ ).
- Multiple contacts (i.e. 4 or more) were often initiated by services. Some steps in the journey may not have been necessary. Of those who sought initial advice from NHS Direct, 79% made further contacts which included 5% that were initially high risk. Initial contact with Emergency Departments led to fewer follow up contacts (42%) despite a third of these being high risk (30%).
- Interestingly, only 11% of parents presented to EDs directly for initial evaluation.
- Of case notes reviewed, most services were recording at least one of the feature types in the NICE guideline for Feverish Illness 'traffic light' system. The child's 'colour' (e.g. flushing or pallor) was the least well recorded. Children at high, intermediate and low risk were triaged appropriately by remote, non-paediatric or paediatric services on 79% of occasions although this varied by service type.
- Overall, parents were satisfied with health professionals who communicated well and reassured them, services that were local, telephone services and having an open access system at hospitals. They expressed some dissatisfaction with waiting times, not being listened to or being dealt with unsympathetically and services not taking into account the practical difficulties families may have when seeking face to face appointments, such as transport.

- A clear message from parents was the need for explicit standardised information about fever, its consequences and management including the point at which to seek medical advice and from where, and which antipyretics to use and how. None of the participants reported receiving a copy of the NICE guideline parent information when asked.

## **Key recommendations**

Overall the urgent care services for children aged less than five years appear to be working well for the majority. However, the frequent contacts for short-lived illnesses suggest certain weaknesses in the service. Key recommendations arising from this report include:

- Parents appear to be aware of the services available to them, and their preference for initial advice is the GP. Facilitating such access to the GP is therefore essential. In addition, resources for promoting services should be tailored towards the needs of the local population.
- Parents of children with self-limiting illnesses offered safety netting advice were less likely to use further services. Thus it is essential that safety netting advice is offered to all parents. The advice should be more specific to the child's condition, i.e. what symptoms / signs the parent should look for, and what should prompt a return to the health provider.
- There is an urgent need for explicit, standardised information regarding febrile illnesses in children (what level of fever is a concern, what symptoms should be looked for, what treatment should be given and in what doses, when medical assessment should be sought). This should be provided in writing, with local contact numbers attached. Other mediums should also be considered<sup>7</sup>, for example, for people who cannot read.
- The above should be widely disseminated, through resources that parents use (such as the 'red book', health visitors, parent websites, social networking sites, other media).
- Based on the findings, we recommend all staff dealing with the urgent care of children in both face to face and remote settings are appropriately trained in the assessment of acutely ill children, sensitive to the needs of parents, and skilled in examining / assessing children.
- Most primary care services did not routinely record all of the observations recommended in the NICE guideline for Feverish Illness. Improved recording of symptoms and signs, and the provider's overall impression, would be of value for future audits.
- We found Research & Development (R&D) approval processes unnecessarily repetitive and time consuming, yielding no improvement in research quality or governance, but significantly impeding the progress and adding to the costs of the project. We appreciate improvements are underway and urge that these are subjected to regular scrutiny and audit to ensure that in future approved research is facilitated.

- The findings of the report would lend itself to the development of Patient Reported Experience Measures (PREM) and commissioning tools to ensure that urgent care services are addressing key issues from a parental perspective.
- Following dissemination of the report and tools and provision of appropriate information to parents, a further review of services in 18 months would be of value to estimate the impact (e.g. reduction in contacts, appropriate triaging) and satisfaction with the service provided.
- The triage tool in the NICE guideline for Feverish Illness should be validated in practice to ensure that the recommended triaging of febrile children is effective at discriminating the sick from the well child.
- A more effective strategy is needed to ensure that the public is aware of NICE's information for parents on feverish illness and how to access it.

# 1. Introduction

## 1.1 Introduction

Children and young people are frequent users of urgent care services,<sup>3,4,5</sup> Despite the fact that the vast majority of childhood illnesses are managed at home without medical intervention<sup>2,6</sup>, children use a large proportion of urgent care services in the UK<sup>4,5,8</sup>. A quarter of calls made to NHS Direct are about children.<sup>2</sup> More than a quarter of visits to Emergency Departments (EDs) nationally are made by children amounting to 2.9 million attendances a year<sup>4</sup> and this number is increasing<sup>9</sup>. In one year, a pre-school child will visit the GP six times, and a child of school age three times<sup>2,3</sup>. Between 1996 and 2006, there was an 18% increase in the number of emergency admissions in children and young people under the age of 20.<sup>10</sup> It is well documented that the needs of seriously ill children are far better met by specialists in child only services<sup>4,11</sup>.

Feverish illness, which may or may not portend serious illness, is very common in young children and is one of the most common reasons for a child to be taken to the doctor. Approximately half of all paediatric admissions to hospital are associated with fever<sup>6</sup>. Parental fear of fever (partly due to the known association with meningitis) and their perception of its severity has been a frequent concern in the relevant literature<sup>12,13,14,15</sup>. Research suggests a range of situational factors that may affect a parent's perception of their child's illness, such as previous negative experiences or family deprivation and education levels<sup>16,17,18,19</sup> and use of urgent care services when their child is ill<sup>20,21,22</sup>. Potentially inappropriate use of secondary care services with non-urgent problems remains an ongoing concern for professionals.

For many children with feverish illness, the initial assessment will be undertaken by their local GP practice, but for other cases, particularly those presenting during the out of hours period, their assessment may be undertaken by providers such as out of hours GP provider, NHS Direct, Walk-in Centres (WICs) and Emergency Departments (EDs). The initial assessments may be carried out face to face or over the telephone and the skills and experience of the assessors in the different organisations can vary considerably. This method of assessment presents significant clinical and organisational challenges. Staff in any setting need to be able to identify which children can be safely assessed and managed at home (i.e. at low risk of serious illness) and which require additional clinical face to face assessment. For this latter group, a decision then needs to be made in relation to how urgent and detailed this additional assessment needs to be and which children need to be actively observed or admitted for treatment<sup>2</sup>. In addition, there is considerable variation in provision of dedicated children's services as opposed to mixed adult and children's services.

Urgent care services for children need to be safe and efficient, and should be appropriately staffed and located. Children should be given a timely assessment by appropriately trained staff with prompt referral to specialist care for the relatively small number who are acutely ill and appropriate follow up arrangements for those who are not deemed to need admission to hospital<sup>2</sup>. Finally, parents and carers need to be given support and information that enables them to care for children with mild illness and to recognise when their child needs an urgent assessment<sup>5</sup>. With the increasing proliferation of urgent care services, both in and out of hours, there is a need to determine whether parents know what services to access, and whether these services are actually meeting the needs of children.

The study draws on the Government's commitment to delivering urgent care services in England that meet the needs of children and their families so they can be appropriately assessed and managed in line with national standards<sup>3,23,24</sup>.

## 1.2 Background to the study

During the consultation on the Department of Health *Direction of Travel for Urgent Care: A discussion document*<sup>6</sup>, concerns were expressed that the needs of children and young people were not being addressed appropriately. Children's needs differ from adults; they need services designed specifically for them, local where possible and specialist where necessary. This ensures that children receive assessment and any necessary treatment in the most appropriate place and are then returned home with support as soon as possible<sup>25</sup>. This pilot study was commissioned by the Department of Health as a result of these concerns.

The study took place over 2008-9 and involved all services providing urgent care in three sites across England: Leicestershire (County and City), Peterborough City and North West London Boroughs. These services included NHS Direct, GP Practices, Out of Hours GP services, Walk-in Centres and Urgent Care Centres, Emergency Departments, Ambulance services, and Children's Assessment Units. A mixed method research design was employed to help understand parent's perception of the pathway for children with febrile illness, as well as provide a snapshot of how urgent care is currently provided using the NICE guideline for Feverish Illness<sup>1</sup> as a framework. This guideline describes the pathway that should be followed for children at high risk, intermediate risk and low risk of serious illness. The study makes recommendations on how urgent care services can be safely delivered within the UK, while ensuring that the service meets the needs of children and their families.

The findings will provide insights for health professionals, information to support commissioners and service providers, and help identify areas that may need further and

more detailed research. They will also provide information for the guideline developer (NICE) to help inform their forthcoming update of this guidance. The work differs from previous research in the area<sup>1,14,16,20,21</sup> by including all urgent care services and exploring the whole patient journey from the parent's perspective. In addition, we have not restricted the study to the sickest children, but rather to all children presenting acutely. Feverish illness was used as an indicator condition to track the child's journey along the care pathway.

This study was undertaken by the Science and Research Department of the Royal College of Paediatrics and Child Health in collaboration with the Royal College of General Practitioners, the College of Emergency Medicine, Joint Royal Colleges Ambulance Liaison Committee, NHS Direct and academic departments of the Universities of Leicester and Nottingham.

### **1.3 Aims and objectives of the study**

The specific study objectives were as follows:

1. To define the current pattern of care for children aged less than five years presenting to primary, secondary or non face to face care with feverish illness.
2. To understand how parents navigate the healthcare service options available to them and provide insights for practice into:
  - Which service parents use for their child with fever and why.
  - How parents navigate through the health system from initial contact to final management, over time.
  - How different service providers facilitate the child's journey along the care pathway and to determine any interface issues / barriers.
  - Whether advice given by services is being followed and if not, why not.
  - What works well and what can be improved from both a parental and a professional perspective.
3. To determine whether urgent care services recognise and assess children with fever in an appropriate and timely way in line with the current NICE guideline for Feverish Illness.
4. To feed back findings to commissioners and providers of urgent care services and to produce recommendations for best practice.

## 2. Methodology

### 2.1 Units Involved

The study was carried out in three sites across England: Leicestershire (County and City), Peterborough City and North West London Boroughs. These areas have a total child (0-15 years) population of approximately 350,000<sup>26</sup>. These sites were facilitated by members of the Project Board; the demography of the sites was similar to that of England, including rural / urban / inner-city, wide socio-economic status and immigrant populations. All services in each site providing urgent care were invited to take part. These were:

- Ambulance services
- Children's Assessment Units (CAUs)
- Emergency Departments (EDs)
- GP Practices (via Primary Care Research Networks).
- NHS Direct
- PCT Out of Hours GP services
- Walk-in Centres<sup>±</sup> (WICs)
- Other primary care services delivering urgent care<sup>‡</sup>

### 2.2 Study population

The study aimed to recruit parents and carers who contacted any urgent care service in the three study sites to seek help for their child aged 0-5 years with a perceived fever (high temperature). At the outset of the study three groups of parents / carers were identified who would not be eligible for inclusion in the study. These were:

- Parents / carers of children with pre-existing disease for which they been given a prior pathway to follow during febrile illness.
- Parents / carers with any complaints or currently involved in a negligence case against the service in question.
- Parents / carers of any children who during the study period died.

Eligibility was determined by health professionals at time of contact and confirmed by the two researchers at first telephone contact with the parent / carer.

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<sup>±</sup>'Walk-in Centre' refers to any primary care service (staffed by GPs or other autonomous practitioners) which provides unscheduled care on a drop in basis.

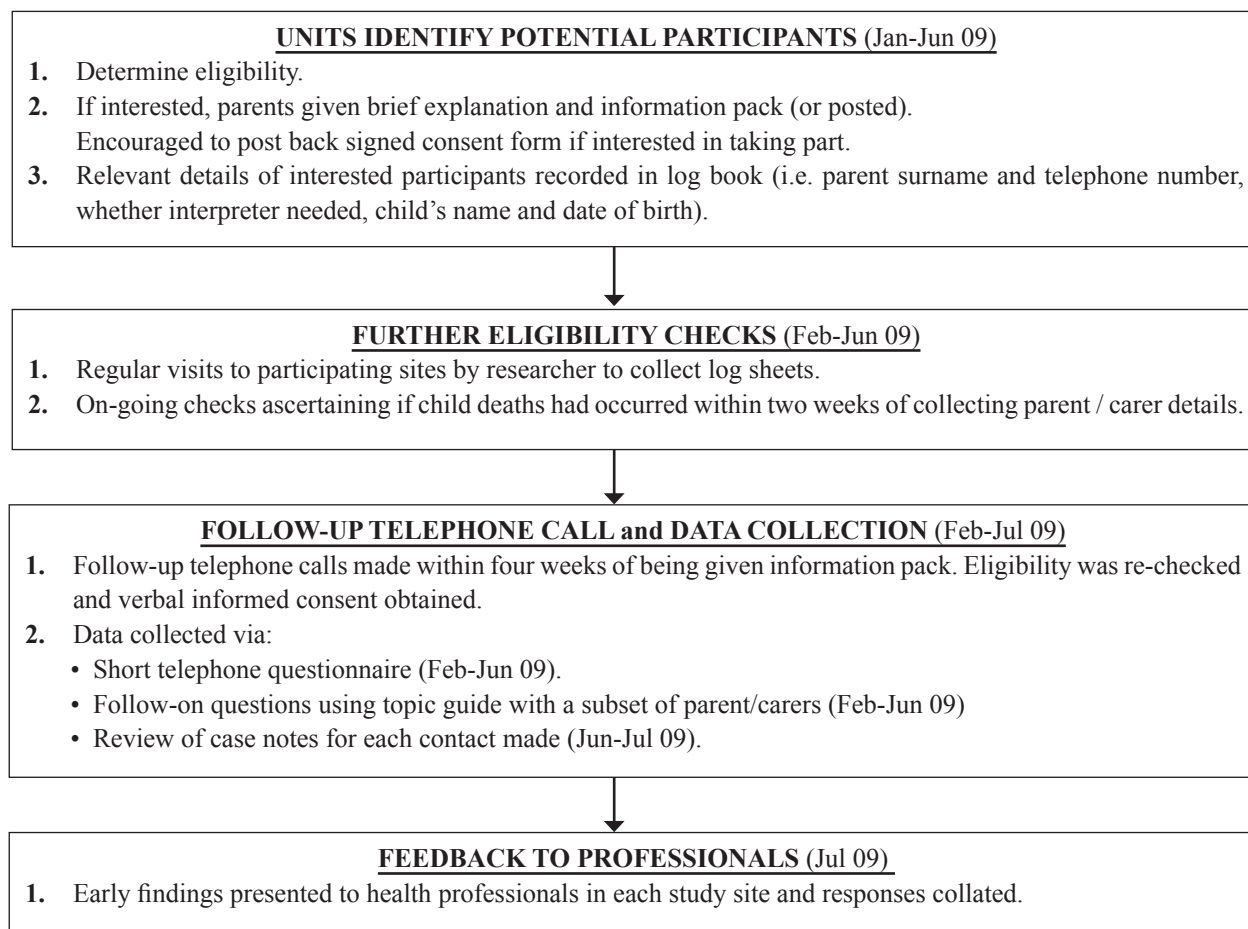
<sup>‡</sup>'Other' primary care services refer to any community based health professional and includes pharmacists, midwives, health visitors. It includes a unit of community paediatric specialist nurses who visit acutely unwell children at home to assess their condition and offer advice and support to parents until the children are better. This service is unique to one region.

## 2.3 Recruitment and data collection

The recruitment and data collection process is shown in Fig. 1. Services acted as ‘participation identification centres’ and began identifying potential participants for referral to the study as soon as the research team had obtained Research and Development (R&D) approval from the relevant body. After assessing the child, health professionals determined whether the parent / carer was eligible (see section 2.2) and interested in the study. If so, an information pack (Appendix 3) was given (or posted if contact was by telephone) and the parent / carer’s details and that of their child were recorded, with permission, on the study log sheet to be collected by the research team.

The researchers visited units regularly throughout the study period to collect any completed log sheets and help resolve any issues arising or queries. The local Coroner or Registrar was then contacted to determine whether there had been any deaths in the 0-5 age group. If so, the researchers checked if any of the details matched the names and dates of birth of children on their list. If there was a match, the protocol dictated that the parent / carer of the child would be excluded and no contact made with the family.

**Fig. 1 Flowchart of recruitment and data collection process.**



Once the researcher had determined that the child was eligible for entry into the study, the parent / carer was telephoned within four weeks of being provided with the information pack. This allowed enough time for the child's illness to evolve while ensuring that parent / carer could still recall their experiences. At least three attempts were made to telephone those parents / carers who expressed interest.

## **Data collection**

Data was collected from three sources: a short telephone questionnaire; medical notes; and, for a subset of parents / carers, a short telephone interview using a topic guide.

Verbal informed consent was obtained and audio recorded with permission before any research procedures were carried out. The child's demographic details were recorded and a short structured telephone questionnaire (Appendix 4) administered for each contact that the parent / carer reported making during that episode of illness. Information was collected about the presenting signs / symptoms (in order to determine the level of risk), worrying features, whether safety netting advice had been given and followed, and the conclusion of the evaluation (e.g. admission, referred to GP). Interpreter services were used with speakers of languages other than English.

At the end of the call, the parent / carer was also asked for permission to review the child's medical notes for each service used during the course of their child's illness. The case note proforma (Appendix 6) was designed to collect more detailed information about presenting signs / symptoms and care provided in order to help determine whether this was in line with recommended practice. Case notes were reviewed by either one of the researchers, a member of the staff from the unit or by the Trust's audit department. Case notes were not reviewed if the unit was in a Trust that had not given R&D approval.

After the questionnaire, some parents / carers were invited to take part in a follow-up telephone interview either at the same time or at a later date. A purposive and opportunistic sampling strategy was used to select a sample of parents across geographical areas (urban, rural and inner-city) and across time points (contacts to a service in working hours, nights or weekends). This stage ended when 'saturation' was reached, i.e. the point at which no new information or themes were observed in the data for each group<sup>27</sup>. The topic guide used for the telephone interviews (Appendix 5) explored: reasons for choosing particular services; experiences of navigating through the health system; whether advice given by services was followed; examples of what worked well and what could be improved; and sources of information that parents seek independently. All parents were offered the opportunity to have feedback on the results of the study.

Towards the end of the data collection period, workshops were held at each site with health professionals from participating units. The aim was to present an overview of parental perspectives and seek professional views on how the urgent and emergency care pathway is currently being navigated by parents / carers.

## **2.4 Target sample size with justification**

Calculation for the sample size used a stratified cluster design for a confidence level of 95%. The clusters were 'hospital' and 'non-hospital' services. For a positive response of 90%, and 5% margin of error, a sample size of 139 was needed. To compensate for the homogeneity of the services the sample size calculation needs to be multiplied by a factor. Examples in literature have used a factor of two, leading to a doubling of the required sample size<sup>28</sup>. Thus the target sample size adjusted for a clustered study design for a 95% confidence interval and 5% level of error was set to 834 (139 x 2 clusters x 3 sites).

However, given the unexpectedly protracted and extensive problems with acquiring local Trust R&D approvals, this sample size was not achievable within the short timescale available and the board decided to use the study as a pilot. As such, any consenting parent / carer within the inclusion criteria was provided with an opportunity to take part. Although the profiles of the participants could not be predetermined due to voluntary participation, it was hoped that the recruitment strategy adopted would yield a sufficient demographic spread.

## **2.5 Analysis**

### **Quantitative Analysis**

Data from the telephone questionnaire and case notes proformas were collated, anonymised and entered onto a Microsoft Excel spreadsheet to generate a separate record for each contact.

Each contact was classified for risk of serious illness by the same researcher (an ED nurse) using the traffic light system recommended in the NICE guideline for Feverish Illness<sup>1</sup>. The contact was classified as high risk if any red signs / symptoms were present, intermediate for amber features and low risk if there were green features and no amber or red features. The list of red, amber and green features can be found in Appendix 1. Any areas of uncertainty were discussed with the Clinical Project lead (a consultant paediatrician) and consensus reached. The classification was done separately for data collected from the questionnaire and for data collected from the case note proformas.

Three inter-reliability checks were carried out. Firstly, five of each researcher's telephone recordings were randomly selected. Each researcher listened to the other's telephone conversation and independently completed the questionnaire form for each contact (18 in total and thus 18 forms completed). The level of agreement between the two researchers on completing the questionnaire and determining which features were present or not using Cohen's kappa statistic ( $\kappa$ ) was high ( $\kappa = 0.87$ ). Second, these features were used to classify the level of risk. The level of agreement for classification of risk based on parental responses was low ( $\kappa = 0.17$ ). Finally, 10% of cases were randomly selected and their questionnaires and case note reviews were independently coded by the consultant paediatrician. The level of agreement between the ED nurse researcher and paediatrician on the classification of risk of serious illness was high ( $\kappa = 0.85$ ).

Deprivation ranks were calculated using data from the Indices of Multiple Deprivation, 2007<sup>29</sup>. Full postcodes, as reported to the researchers by parents / carers, were matched to Lower level Super Output Areas (LSOAs)<sup>30</sup> giving each a rank and 'score' or measure of deprivation across several domains. The number of participants living in each of the quintiles relating to deprivation and standardised for age<sup>26</sup> was identified.

Descriptive statistics were used to summarise the data. For categorical variables, frequencies and percentages are presented and for continuous variables, the total n, median and range presented. Data were analysed using the Statistical Package for Social Sciences (SPSS). Association between different variables was tested by Chi-square ( $X^2$ ) tests. The units that took part in the study were grouped by service type in order to preserve anonymity.

### **Qualitative Analysis**

The responses of the 29 parents / carers who answered follow up questions were recorded and transcribed. Content analysis and QSR NVivo software were used to analyse the transcriptions to identify any patterns and themes<sup>27</sup>. The responses to the questionnaire item, "What was worrying you most about your child at the time?" were entered as free text and categorised by the ED nurse.

## **2.6 Research governance and ethics**

The study was approved by the St Thomas' Hospital Research Ethics Committee in October 2008 (ref. 08/H0802/119) and a substantial amendment to collect the child's name and date of birth (to ascertain if a death had occurred), was approved in December 2008. Research

and Development approval and letters of access were obtained from the relevant NHS Trusts (including approval from information governance departments in some areas) and the study adopted onto the UKCRN and Primary Care Research Network portfolios.

The study was overseen by the Project Board (see front of report for list of members) who met regularly throughout the study duration.

The term “parent” is used in the remainder of the report to refer to parents or carers.

## 3. Results

### 3.1 Recruitment and characteristics of participants

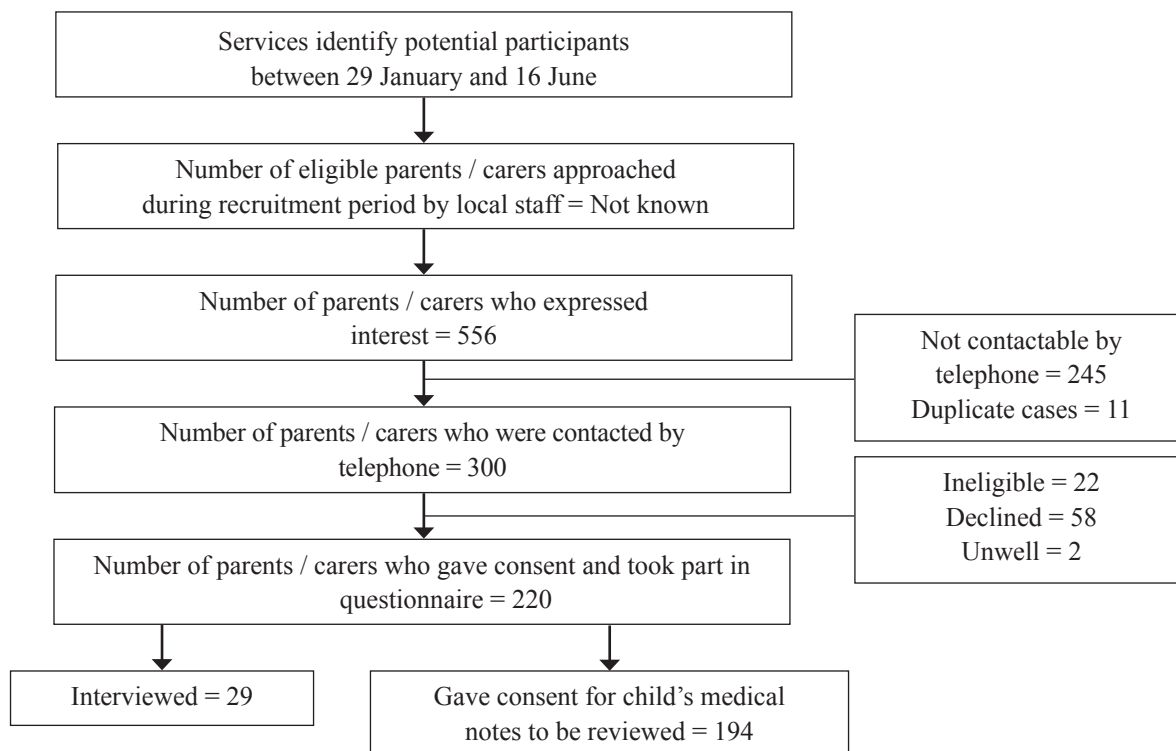
A total of 34 services agreed to act as participant identification centres. Services began identifying potential participants as soon as R&D approval was obtained which varied in each area. In total, 12 R&D approvals were obtained following central ethical approval. Leicestershire and Peterborough units identified potential participants from 29 January to 31 May and London units from 2 March to 16 June. Seven units did not identify any potential participants, including all three ambulance Trusts.

During the study period, 556 parents expressed interest in the study (see Fig. 2). A total of 245 were unobtainable within a reasonable time frame (including 27 with an incorrect telephone number) and 11 were duplicate cases. Of the remaining 300 contactable and eligible participants, 220 (73%) consented and took part in the telephone questionnaire (dataset 1). Reasons for not taking part were that: the child remained unwell at the time of interview (2), the child was determined to be ineligible (20) or the parent refused (58). None of the children whose parents had expressed interest died. Of the 220 participants, 194 consented to their child's medical notes being reviewed (dataset 2).

A total of 29 of the 220 took part in a follow-up telephone interview (dataset 3). The sample included a mix in terms of geographical area (urban, rural and inner-city), ethnicity, socio-economic status, number of contacts made, level of risk of serious illness, types of services used and in and out of hours (see Appendix 2 for summary profile). Parent's age and educational level were not recorded. Key themes are illustrated here with verbatim quotations. Details of participants' profiles have been omitted to ensure confidentiality.

The number of children who contacted the urgent care services and were approached by health professionals about participating in the study during the data collection period is not known. However, as an estimate for 0-5 year olds during the study period, there were 562 attendances (any reason) to one of the CAUs, approximately 685 attendances to one of the Emergency Departments for fever / temperature and 26,000 NHS Direct calls for fever related illness.

**Fig. 2. Recruitment**



**Description of sample**

Almost two thirds of parents were recruited from Leicestershire (County and city) (Table 1). Parents were fairly evenly recruited from primary and secondary services.

**Table 1. Recruitment characteristics of parents (N=220)**

Recruitment	Sample N 220 (%)
<b>Site</b>	
Leicestershire	140 (63%)
Peterborough	48 (22%)
North West London	32 (15%)
<b>Service type</b>	
<i>Primary care</i>	
GP	128 (58%)
Out of Hours GP service	41 (19%)
Walk-in Centre	14 (6%)
NHS Direct	29 (13%)
Ambulance	32 (15%)
Other*	0
<i>Secondary Care</i>	
Emergency Department	12 (5%)
Children's Assessment Unit	92 (42%)
	48 (22%)
	44 (20%)

\* 'Other' primary care services refer to any community based health professional and includes pharmacists, midwives, health visitors. It includes a unit of community paediatric specialist nurses who visit acutely unwell children at home to assess their condition and offer advice and support to parents until the children are better. This service is unique to one region.

Over half (59%; 130/220) of the sample were aged 1-4 years, 27% were aged 0-12 months and 14% aged 4-5 years (Table 2). The sample included a higher proportion of children from ethnic minorities in the sample compared to the population of England. The percentage of participants living in England's quintiles of deprivation from most deprived to least deprived was similar to that of the overall population of 0-15 year olds.

**Table 2. Demographic characteristics of children included in the sample (N=220) compared to population for England<sup>2, 29,31</sup>.**

<b>Characteristics</b>	<b>Sample N 220 (%)</b>	<b>England N-1000s (%)</b>
<b>Age of child at first assessment</b>		
0 to <=1 years	60 (27%)	0-1 years: 641 (21%)
13 mths to <=2 years	62(28%)	
25 mths to <=3 years	39 (18%)	1-4 years: 2,528 (79%)
37 mths to <=4 years	29 (13%)	
49 mths to <=5 years	21 (10%)	
61 mths to < 6 years	9 (4%)	
Girls	97 (44%)	1,482 (49%)**
<b>Ethnic origin of child</b>		
White British	131 (60%)	42,747 (87%)
White Other	19 (9%)	1,932 (4%)
Mixed	20 (9%)	643 (1%)
Asian	32 (14%)	2,248 (5%)
Black	13 (6%)	1,133 (2%)
Other	5 (2%)	435 (1%)
<b>Length of episode</b>		
0-24 hours	45 (20%)	
25-48 hours	40 (18%)	
49-72 hours	26 (12%)	
>73 hours	95 (43%)	
Unknown	14 (6%)	
<b>Indices of Multiple Deprivation Rank*</b>		
0-20% (most deprived)	40 (20%)	
20-40%	35 (18%)	
40-60%	32 (16%)	
60-80%	37 (19%)	
80-100% (least deprived)	52 (27%)	

\* Known for 196 children

\*\* Aged 0-4 years

## 3.2. Services used and pathways followed

### 3.2.1 How many contacts did parents make during the illness?

Overall, the 220 parents made a total of 570 contacts (median 3, range 1-13) across primary and secondary care services throughout the child's illness. The child's illness was relatively short lived in many cases, lasting 3 days on average (range < 24 hours to > 73 hours). Over a third of parents (39%; 85) reported seeking advice within 24 hours of their child becoming ill, 23% (50) waited between 25-48 hours and 37% (81) waited 49 hours or more. The remainder (2%; 4) did not know how long they had waited before seeking advice.

Most (70%; 155/220) parents had more than one contact with urgent care services involving 505 contacts in total. Most of the repeat contacts (i.e. not first) were initiated by the urgent care services themselves (221 of 350). This included parents either being referred or admitted to another service or given a follow up / outpatient appointment.

The 220 parents gave a total of 536 different responses to the question, "What was worrying you most at the time [of contact]?"\*; most reported more than one concern (Table 3).

**Table 3. Concerns at time of presentation (536 responses)\***

Concern	Number of responses
Fever or high temperature	202
Specific infection e.g. tonsillitis	43
Rash	39
Vomiting	30
Length of illness, continuing symptoms or no improvement	26
Change in behaviour or level of consciousness	25
Worsening symptoms or deterioration	25
Cough	24
Diarrhoea	24
Loss of appetite, not eating or weight loss	24
Breathing problems	19
Not drinking or dehydration	15
Fits, seizures or febrile convulsions	14

\* Most parents gave more than one response.

NB: Although all children had a feverish illness at first contact, concerns for subsequent contacts may not have been primarily triggered by pyrexia.

### 3.2.2 Which urgent care services did parents use for initial advice for their child and why?

Parent's preference for initial advice overall (43%; 94/220), and particularly when presenting 'in hours' (67%; 93/138), was to see their GP (Table 4). When not available, approximately half chose to contact NHS Direct (46%; 38/82). Only 11% (24) of parents brought their child directly to the Emergency Department (ED) for initial advice; 4 were perceived to be at high risk of serious illness by the parent.

**Table 4. Parent's preference for initial advice (n=220) in and out of hours.**

	<b>In hours</b>	<b>Out of hours</b>	<b>In and Out of hours Total n (%)</b>
<b>Primary care</b>	<b>126 (91%)</b>	<b>70 (85%)</b>	<b>196 (89%)</b>
GP	93 (67%)	1 (1%)	94 (43%)
OOHs GP	0	11 (13%)	11 (5%)
WIC	19 (14%)	15 (18%)	34 (15%)
NHS Direct	9 (7%)	38 (46%)	47 (21%)
Ambulance	4 (3%)	4 (5%)	8 (4%)
Other*	1 (1%)	1 (1%)	2 (1%)
<b>Secondary Care</b>			
ED	12 (9%)	12 (15%)	24 (11%)
<b>Total</b>	<b>138</b>	<b>82</b>	<b>220</b>

NB: CAUs can only be accessed via a referral from another service provider.

\* 'Other' primary care services, refers to any community based health professional and includes pharmacists, midwives, and health visitors. It includes a unit of community paediatric specialist nurses who visit acutely unwell children at home to assess their condition and offer advice and support to parents until the children are better. This service is unique to one region.

### 3.2.3 Which services did parents use at any point in the illness and why?

Of the 570 contacts, 74% (422) were with primary care services (Table 5). The most frequently used services were GP/OOHs GP (37%, 210), followed by 'other' primary care services (15%; 85), Walk-in Centres (10%, 55) and NHS Direct (10%; 57). Fifteen (3%) contacts were calls to the ambulance service of which 9 were for children with a febrile convulsion. A quarter of the contacts (26%) were to secondary care services (CAU or ED).

**Table 5. Parent's use of services at any point in the illness (n=570 contacts).**

	<b>In hours</b>	<b>Out of hours</b>	<b>In and Out of hours Total n (%)</b>
<b>Primary care</b>	<b>268 (75%)</b>	<b>154 (73%)</b>	<b>422 (74%)</b>
GP	175 (49%)	3 (1%)	178 (31%)
OOHs GP	0	32 (15%)	32 (6%)
WIC	26 (7%)	29 (14%)	55 (10%)
NHS Direct	14 (4%)	43 (20%)	57 (10%)
Ambulance	7 (2%)	8 (4%)	15 (3%)
Other*	46 (13%)	39 (18%)	85 (15%)
<b>Secondary Care</b>	<b>90 (25%)</b>	<b>58 (27%)</b>	<b>148 (26%)</b>
ED	43 (12%)	40 (19%)	83 (15%)
CAU	47 (13%)	18 (8%)	65 (11%)
<b>Total</b>	<b>358</b>	<b>212</b>	<b>570</b>

\* 'Other' primary care services refer to any community based health professional and includes pharmacists, midwives, health visitors. It includes a unit of community paediatric specialist nurses who visit acutely unwell children at home to assess their condition and offer advice and support to parents until the children are better. This service is unique to one region.

Interview participants (dataset 3) gave a range of reasons for using particular services. These included: the age and illness history of the child, level of concern at the time, availability of their own GP, whether they thought the child's illness required face to face attention, need for reassurance, previous experiences (both positive and negative) and the inconvenience associated with hospital waits.

The need for reassurance and advice about whether the child could be managed at home or whether the symptoms were more serious and the child needed to be seen by a medical professional was a strong theme in the interviews. A number of parents reported that they used the NHS Direct telephone service or website for this reason, particularly if it was out of hours. One parent explained their reasons for calling NHS Direct:

*Just for reassurance really and just to make sure that, you know, somebody else's opinion. Because you know what it's like when you've got kids you feel guilty for taking them to the doctors and guilty for not, so as it was the evening I thought I'd ring the NHS Direct and see what advice they had. (Parent of 3-year-old, 2 contacts, out of hours.)*

Parents reported that they would first seek advice from their local GP if they could get a same day appointment. Reasons included: belief that the GP was the first medical professional to contact when a child is ill, the child would be seen quicker than by other services, for a second opinion, level of concern and felt to be more personal as the GP already knew the child and their history. One parent commented on their reasons for contacting their GP:

*Yes, they always seem to...like normally it seems like they look back on your records or something so they know everything that's happened so when you walk in it feels like a more personal meeting and they just seem like they know everything about you which is quite nice and makes you feel more relaxed when you're talking to them. It just seems there it's much of a friendly family place. (Parent of 9-month-old, 1 contact, in hours.)*

The doctor-patient relationship was also felt to be important and listening skills were valued. One parent explained that this was why she preferred a particular GP, and was disappointed when she could not get an appointment with them:

*Because she is very sensitive. She always listens to what we've said, and she gives us advice and suggestions. To us, other doctors just talk, talk, talk, they don't listen to us. She is always very helpful so we like to see this doctor especially. (Parent of 4-month-old, 1 contact, in hours.)*

Convenience, including proximity, were other reasons mentioned for using one service instead of another, particularly if it was outside surgery hours. One parent explained why they had used the Walk-in Centre for initial advice:

*Yeah we live in a small village and our Out of Hours surgery is 20 miles down the motorway and you have to ring up and make an appointment beforehand, and we've spent hours there having two young children, so it's easier and quicker to use the Walk-in Centre at xxx which is a lot nearer, than use our Out of Hours surgery. If it's in the week and our doctor's surgery is open obviously we'd use that, it was just because it was a weekend. (Parent of 5-year-old, 2 contacts, in and out of hours.)*

Participants frequently referred to their own parental experience, level of confidence and knowledge of fever / temperature in children. This influenced which service they used:

*If he had a fever, I wouldn't take him straight to the hospital, just for the general fact that I know he's not an emergency. If I knew myself, because obviously you know how ill they are, if they are really poorly then I probably would take him to hospital, but if he just had a temperature I wouldn't. (Parent of 10-month-old, 4 contacts, in and out of hours.)*

There was a common concern about possible meningitis. This was one reason for parents going directly to the hospital for initial advice about the child's rashes. One parent commented:

*Yes I just felt the way the nurses [at a Walk-in Centre] were was, 'oh it's just a virus she'll be fine' and just carry on with what you are doing. But when we got home and she got worse I was beginning to doubt... they didn't listen to her chest, they looked in her throat but they didn't look in her ears, or check she could put her chin on her chest, checking for meningitis, because that's what was at the back of my mind, because it could be that one time you don't take them [to doctors] that it could be meningitis couldn't it. (Parent of 5-year-old, 2 contacts, in and out of hours.)*

### **3.2.4 How ill was the child on presentation to the service?**

The level of illness severity was stratified by applying the 'traffic light' system in the NICE guideline for Feverish Illness<sup>1</sup> to the parental report and the health professional report via case notes (where they could be obtained). This was done in order to assess whether the guideline standards had been met (see section 3.2.8) and to provide insights into which services parents use when their child is perceived to be at high, intermediate and low risk.

The level of agreement between the parent and health professional report was low ( $\kappa=0.06$ ), with parental perception of illness severity being greater than the professional's.

As shown in Table 6, most children who presented to primary care services other than the ambulance were at intermediate risk (68%; 253/373) or low risk (24%; 89/373) according to the parent. Ambulances were mainly used when parents perceived their child to be very sick (high risk) (69%; 9/15).

There were 83 attendances to Emergency Departments. Of these, 40 were referred by another service or were brought in by ambulance; 37 were perceived to be at high or intermediate risk by the parent.

**Table 6. Type and number of contacts by level of risk of serious illness based on parent report (n=529) or health professional report via case notes (n=220).**

	Parent Report				Health professional (HP) report via case notes			
	High Risk	Intermediate Risk	Low Risk	Parent Report Total	High Risk	Intermediate Risk	Low Risk	HP Report Total
Number of contacts	80	348	101	529	13	82	125	220
Median (Range)	4 (1-9)	3 (1-13)	4 (1-13)		4 (2-13)	5 (1-13)	3 (1-13)	
<b>Services used</b>								
<b>Primary care</b>	<b>40 (10%)</b>	<b>257(67%)</b>	<b>89 (23%)</b>	386	<b>6 (4%)</b>	<b>60 (39%)</b>	<b>86 (57%)</b>	152
GP	17 (10%)	112(63%)	48 (27%)	177	1 (4%)	7 (30%)	15 (65%)	23
OOH GP	4 (13%)	24 (80%)	2 (7%)	30	0	6 (86%)	1 (14%)	7
WIC	3 (5%)	44 (80%)	8 (15%)	55	0	10 (38%)	16 (62%)	26
NHS Direct	4 (7%)	44 (79%)	8 (14%)	56	0	3 (12%)	23 (88%)	26
Ambulance	9 (69%)	4 (31%)	0	13	2 (25%)	4 (50%)	2 (25%)	8
Other	3 (5%)	29 (53%)	23 (42%)	55	3 (5%)	30 (48%)	29 (47%)	62
<b>Secondary Care</b>	<b>40 (28%)</b>	<b>91 (64%)</b>	<b>12 (8%)</b>	143	<b>7 (10%)</b>	<b>22 (32%)</b>	<b>39 (57%)</b>	68
ED	20 (25%)	51 (63%)	10 (12%)	81	3 (7%)	14 (34%)	24 (59%)	41
Assessment unit	20 (32%)	40 (65%)	2 (3%)	62	4 (15%)	8 (30%)	15 (56%)	27
<b>Outcome of contact+</b>								
Service referred on, further contact made	48 (25%)	128 (66%)	18 (9%)	194	9 (8%)	56 (52%)	43 (40%)	108
Stayed home, no further contact*	18 (9%)	133 (64%)	57 (27%)	208	4 (5%)	20 (26%)	54 (69%)	78
Sent home, sought further contact**	14 (11%)	87 (69%)	26 (20%)	127	0	6 (18%)	28 (82%)	34
<b>Of those sent / stayed at home:</b>								
Parent reported given safety-netting advice	28 (10%)	184(68%)	60 (22%)	272	4 (4%)	25 (25%)	70 (71%)	99
Not given	3 (5%)	33 (59%)	20 (36%)	56	0	1 (9%)	10 (91%)	11
Parent did not know	1 (14%)	3 (43%)	3 (43%)	7	0	0	2 (100%)	2

**NOTES:**

The denominator used to calculate percentages is the row total for parent report or health professional report. The information from health professional report note and parent report do not necessarily relate to the same child.

+ According to parent report

\* Includes parents who were referred on or told to see another professional but the parent decided to keep child at home.

\*\* Includes parents who were given open access or told to re-attend if the child did not progress appropriately.

### 3.2.5 What happened after the initial contact?

Figures 3a to 3d describe the pathways followed by parents who initially sought advice from GP services, NHS Direct, Walk-in Centres or the Emergency Department. The diagrams show the service first used and each subsequent contact grouped as either primary care (i.e. GP, OOHs GP, WIC, NHS Direct, Ambulance or 'other' primary care) or secondary care (ED or CAU) up to the fourth contact. The arrows show whether the contact was a result of a referral by a service according to the parent (solid arrow) or the parent sought further advice, i.e. self-referred (broken arrow). An example of how to interpret the diagrams is given below.

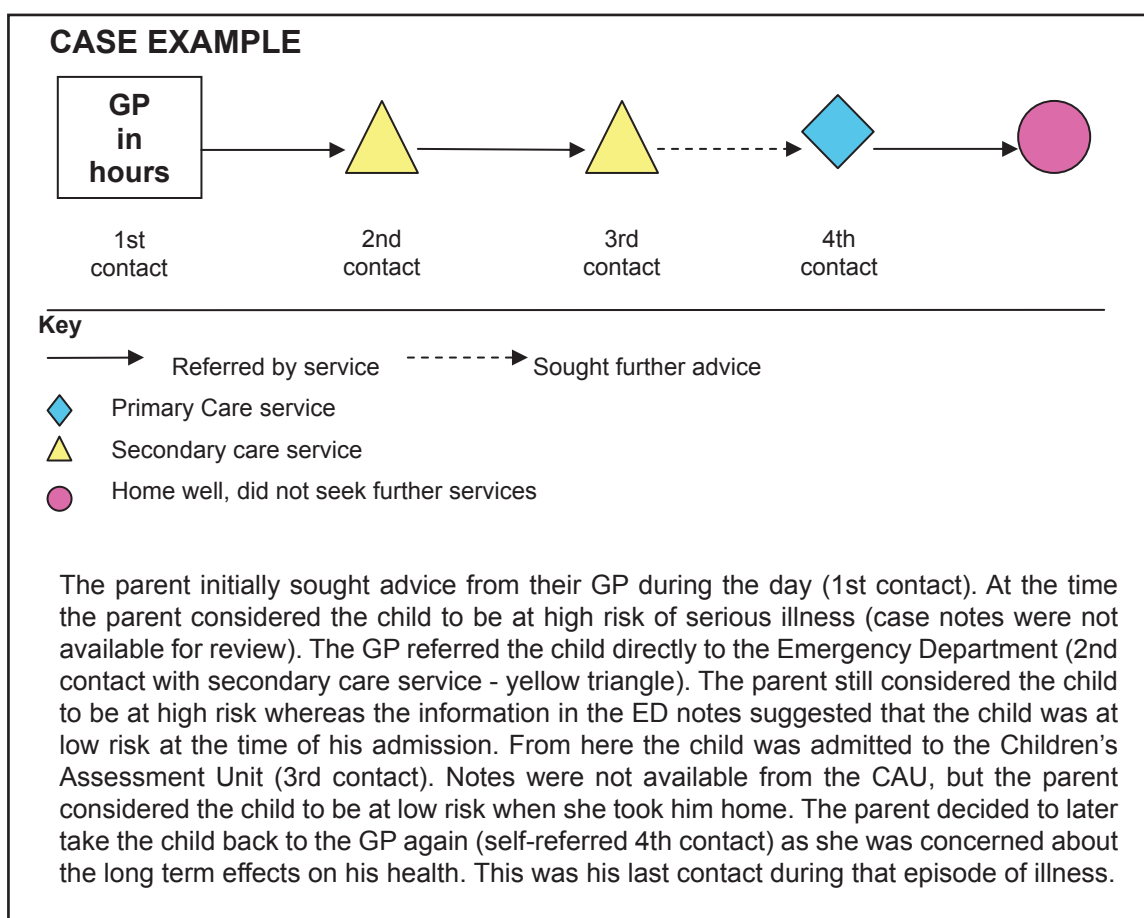


Table 7 summarises the pathways and presents the number who initially sought advice from each of the key services, the number who stayed home without seeking further contact and the number who made frequent contacts, and, for each, the number who were initially high risk according to the parent (the remainder were low or intermediate risk or risk status could not be determined).

Of those who initially sought advice from the GP / OOHs GP (105), 73% (77) went on to have further contacts of which 17% (13) were initially high risk. Nearly half re-attended the same service (47%; 36/77).

Of those who initially sought advice from WICs, 62% (21/34) went on to have further contacts including two (10%) that were initially high risk.

For NHS Direct, 79% (37) made further contacts of which 5% (2) were high risk.

Initial contact with Emergency Departments led to fewer follow up contacts (42%; 10/24) despite a third of these being high risk (3/10). Of the 10, three were admitted.

Thus, NHS Direct had the lowest level of high risk children, but made the largest number of onward referrals.

**Table 7. Children presenting as high risk of serious illness according to parent report.**

	Number who first sought advice from this service (number high risk)	Number stayed at home well after the first contact (number high risk)	Number who made 4 or more contacts* (number high risk)
GP (incl. OOHs)	105 (13)	28 (0)	24 (5)
NHS Direct	47 (2)	10 (0)	8 (0)
WIC	34 (3)	13 (1)	6 (1)
Emergency Departments	24 (4)	14 (1)	2 (0)
Ambulance and other services	10 (5)	0	4 (2)
Total	220 (27)	65 (2)	44 (8)

\*The four or more contacts could be with services other than the presenting service;

Note: Children initially presenting as high risk may not have been high risk at subsequent contacts and vice versa

### 3.2.6 Were parents given 'safety netting advice' and was it followed?

Of the 349 sent home or who kept their child at home, 284 (81%) recalled being given safety netting advice, i.e. told what to do if their child did not progress as expected, 56 did not and 9 did not know if they were given such as advice. Most of the 284 who went home with safety netting advice, followed the advice given and stayed at home (65%; 186). A small proportion (7%; 20/284) returned to the service as advised because the child did not progress as expected.

Parents who did not receive safety netting advice were more likely to seek another contact than those who did (52%; 29/56 vs. 35%; 98/284, p=0.01). The proportion of parents given safety netting advice varied according to parent reported risk levels (high: 90%; intermediate: 85%; low: 75%).

Some interview participants (dataset 3) commented on the safety netting advice given and why they had or had not followed it. Some parents reported that they had been given helpful advice on what to look for and where to go if the child did not get better. However, others felt they had not or that the advice was not helpful, or could not remember. In the following two case studies, the parent appears not to have received clear safety netting advice in relation to what to look out for which may have contributed to their anxiety. One parent commented that she would have liked written information about what signs to look for at the time and that it was often difficult to retain spoken information when going through the experience in the hospital. The parent also suggested including some information about fever in children's 'red books'.

**CASE STUDY 1**

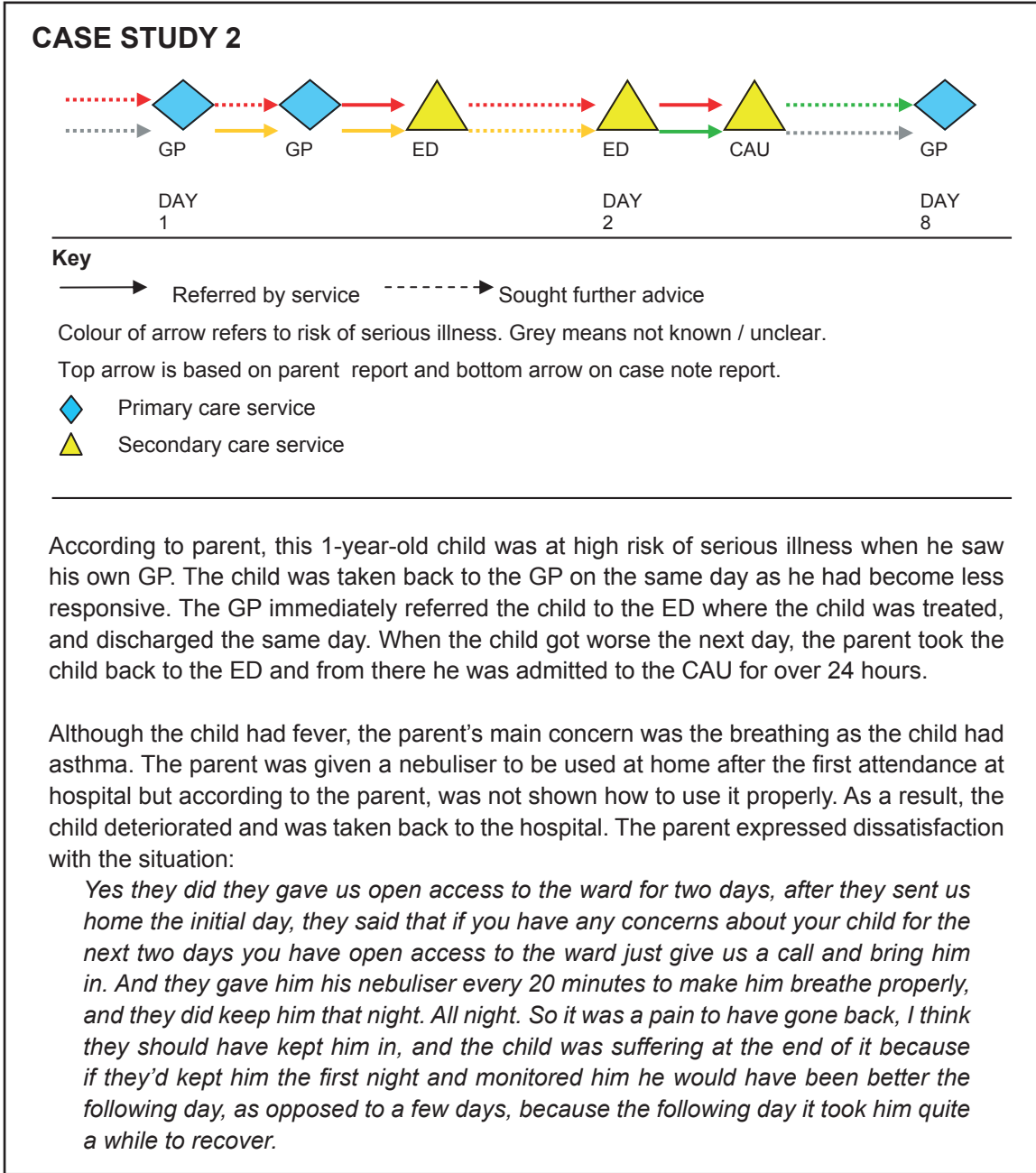
**Key**

- Referred by service      - - - - -> Sought further advice
- Colour of arrow refers to risk of serious illness. Grey means not known / unclear.
- Top arrow is based on parent report and bottom arrow on case note report.
- ◆ Primary care service
- ▲ Secondary care service
- R = Remote primary care service

This 5-month-old baby's parent telephoned NHS Direct for advice, because although she felt the baby was not very sick, she had a persistent cough. Two weeks later the baby became quite short of breath so the parent took them to the GP, who sent them to the ED. The baby was treated and discharged the same day (with safety netting advice). Three days later the baby had deteriorated. The parent was not sure what to do so checked the NHS Direct website which advised her to call 999 straight away. She chose not to do this, and drove the baby to the ED where the baby was admitted to the hospital for several days with pneumonia.

The parent reflected on their own advice seeking pattern and said that they rang the NHS Direct 'because I didn't want to waste my GP's time' and also stated:

*Yeah. I mean I was concerned; my issue with it was that being a full time mother having been sent home from hospital means that you question your concerns from thereon. I was told it was a virus and it would take 3-5 days which is why I was sort of reluctant to go back. So I slightly question having been sent home as quickly on the Monday, and I would have preferred if someone had even given me an A4 information leaflet on what to look for, that would have been much more helpful to me. I was just told she's okay, she probably has a virus, and obviously she didn't have a virus she had pneumonia. Of course I would have come back, but if somebody had said, these are the key things to look for that would have been very helpful, because I just had to rely on my instincts because obviously I'm not medically trained.*

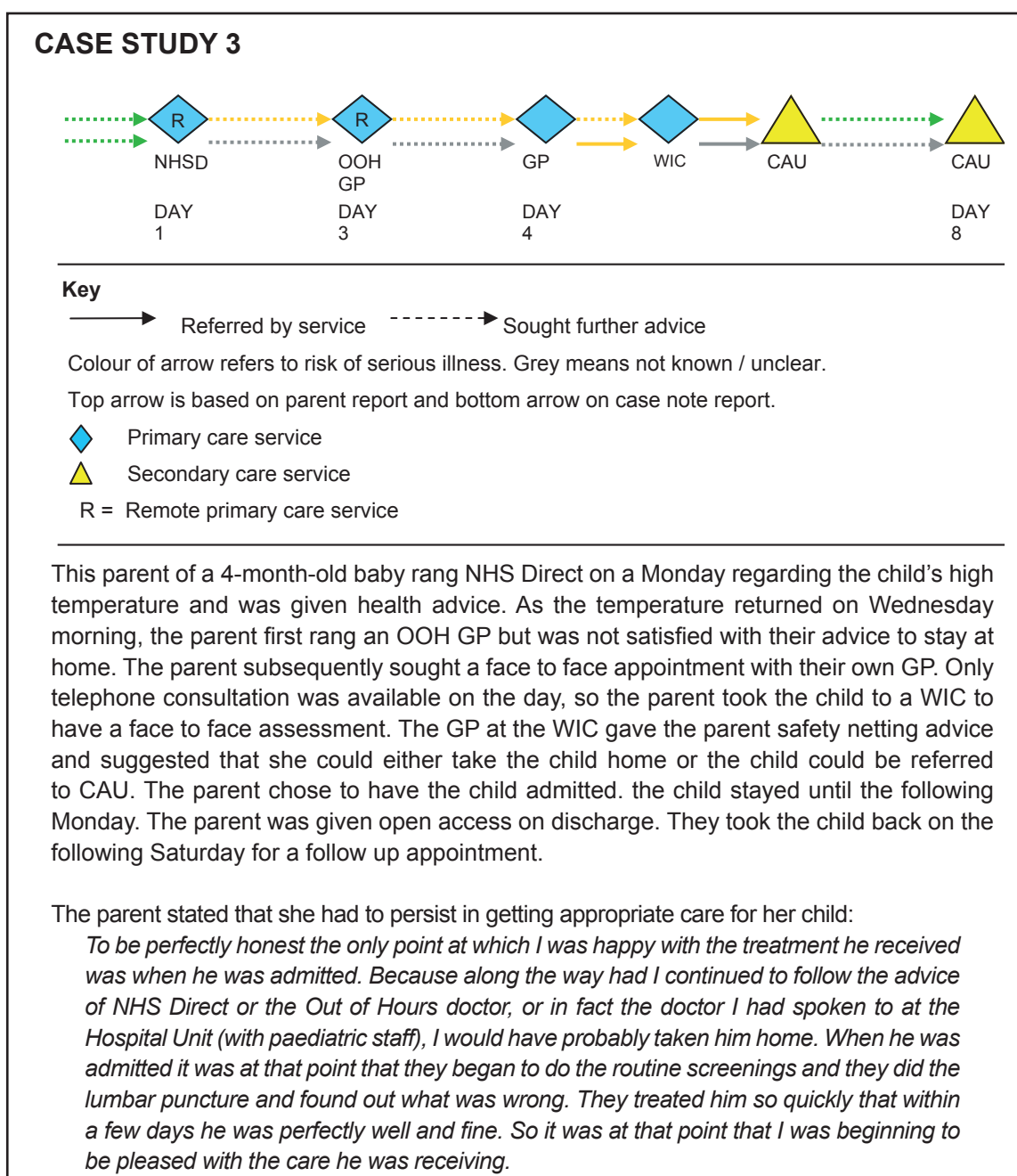


### 3.2.7 Frequent contacts with services

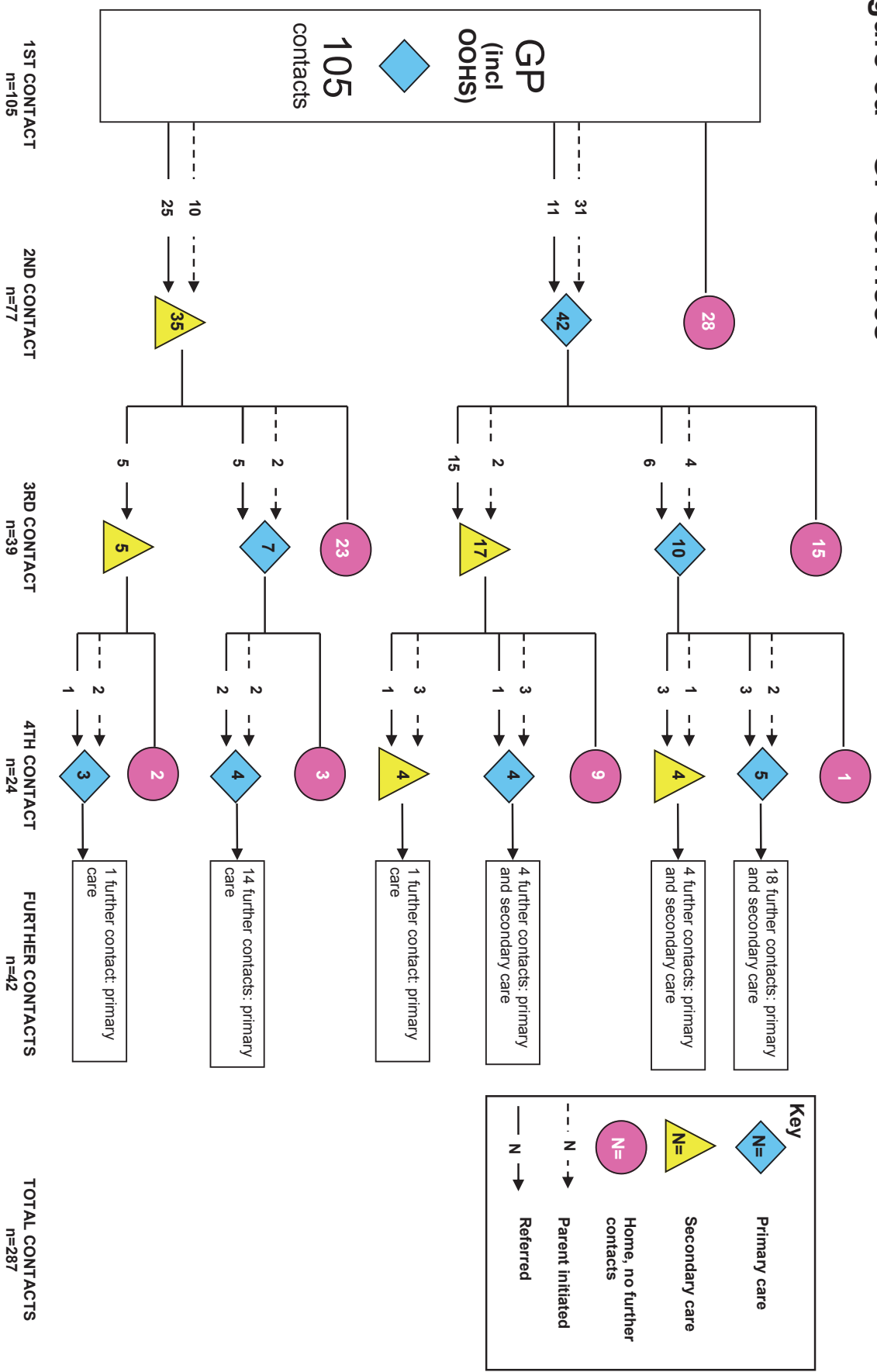
The majority of parents (80%; 176/220) made 1-3 contacts with services during the episode of illness. A total of 44 parents made four or more contacts (including 3 who had ten or more) which accounted for 249 of the 570 contacts. Overall, referrals between services accounted for 68% (139/205) of subsequent (i.e. not initial) contacts. A total of 71 (made by 14 individuals) were with a single team of community paediatric specialist nurses who visit acutely unwell children at home with the aim of reducing admissions. This service is unique to the specific location and the visits are not necessarily initiated by the parent. The parental determination of risk was available for 41/71 cases, being high

risk on two occasions, intermediate risk on 20 and low risk on 19. The health professional determination of risk where known (62/71) was 3 high risk, 30 intermediate risk and 29 low risk. Thus this service had only 3% high risk cases.

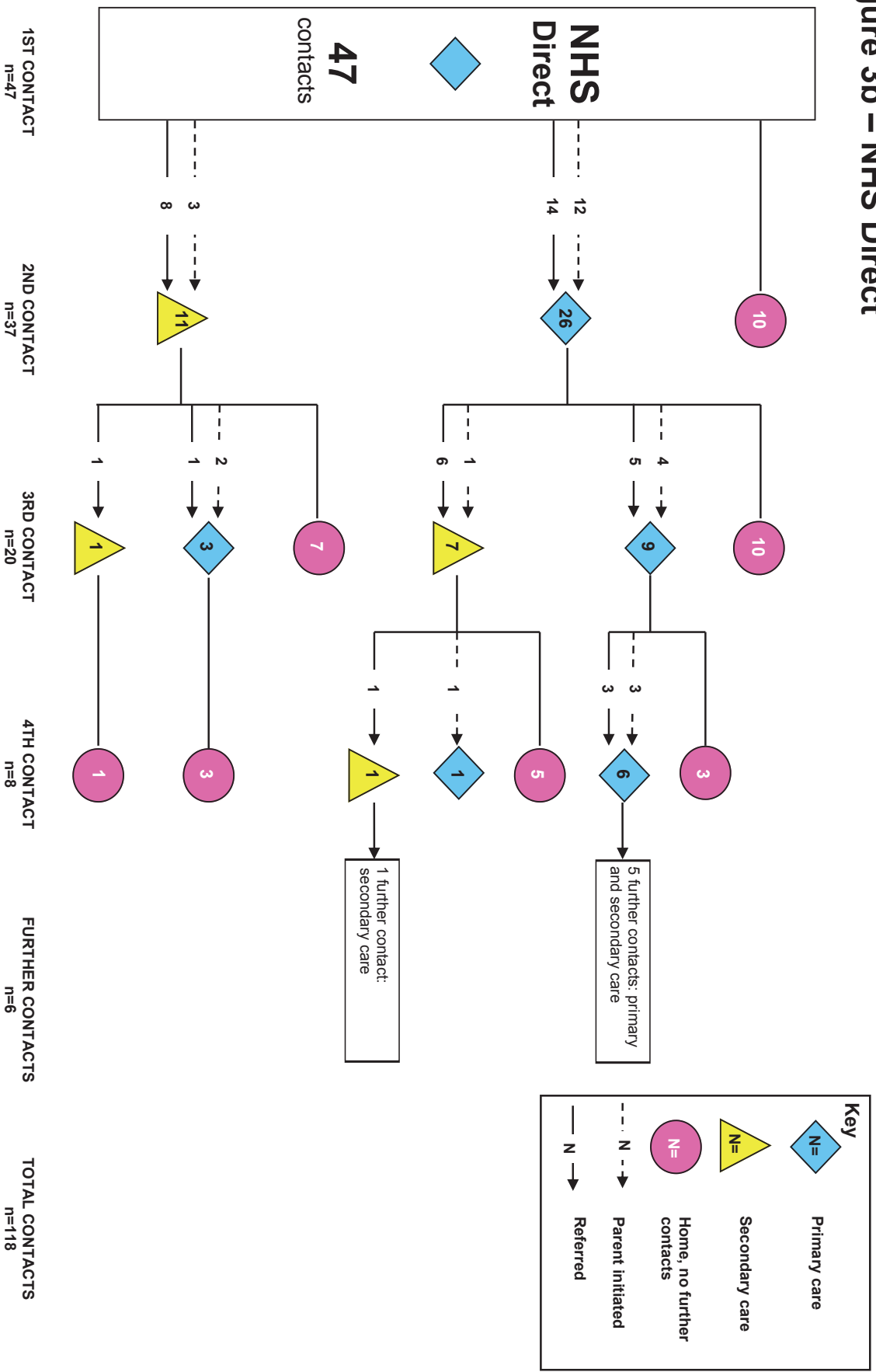
The example below illustrates the context for multiple contacts with services in one case. This parent commented during their interview that because they obviously knew their child very well and knew something wasn't quite right, they persisted in trying to get the appropriate care. This parent was knowledgeable about the services available in their local area and said that if it happened again, in future they would use the primary care service which had a 24 hour GP and would cut out the early steps.



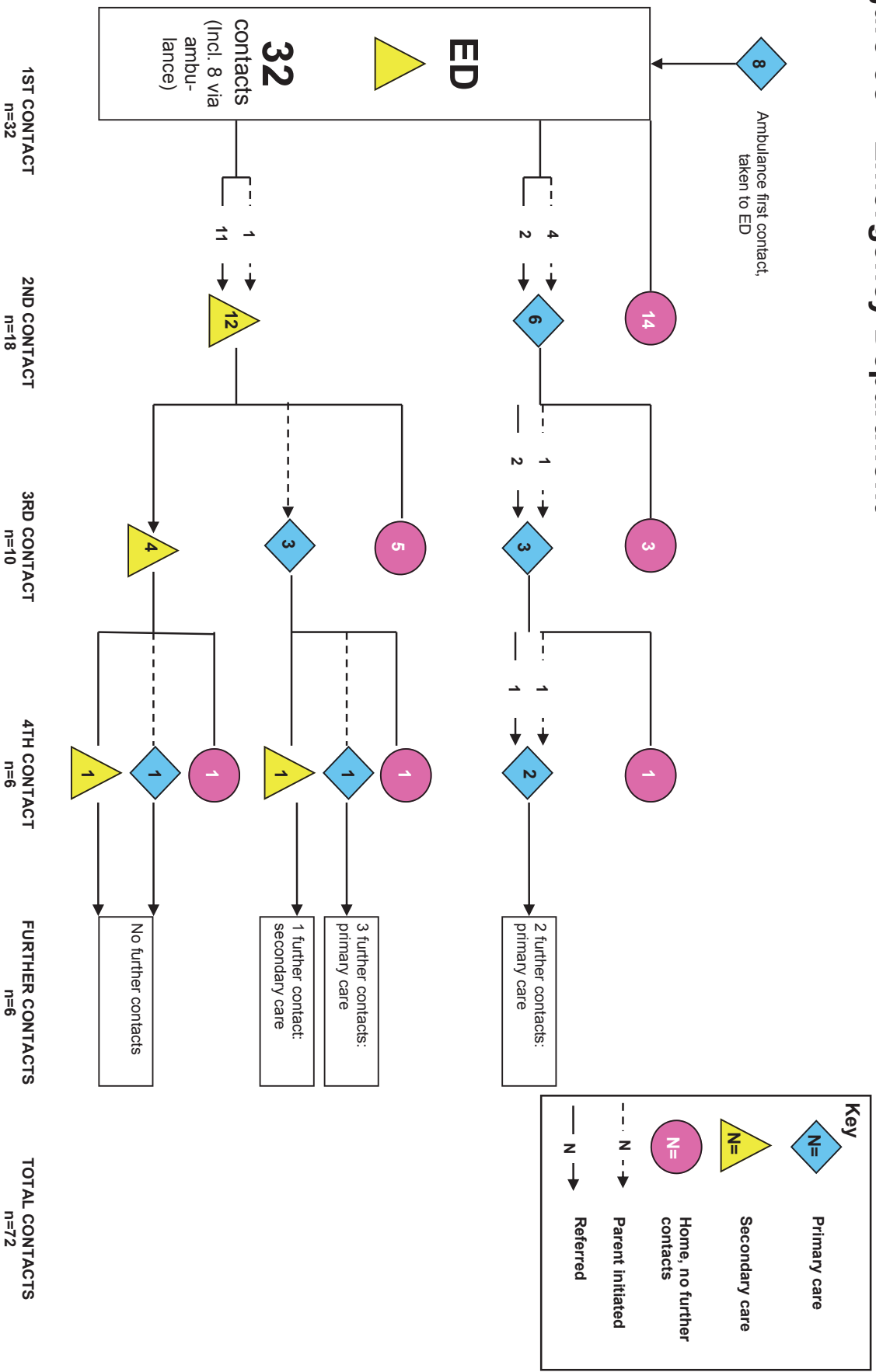
**Figure 3a – GP services**



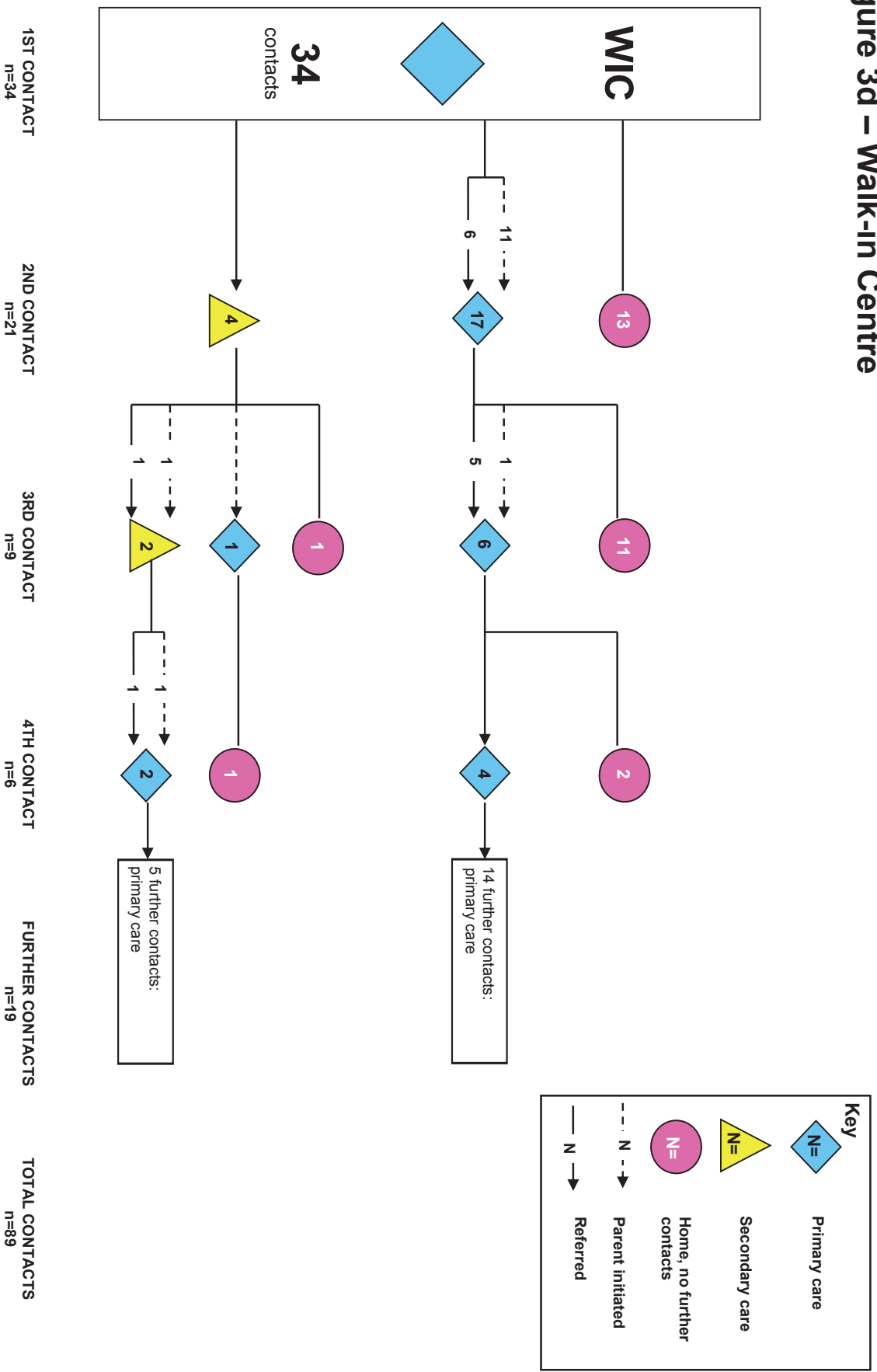
**Figure 3b – NHS Direct**



**Figure 3c – Emergency Department**



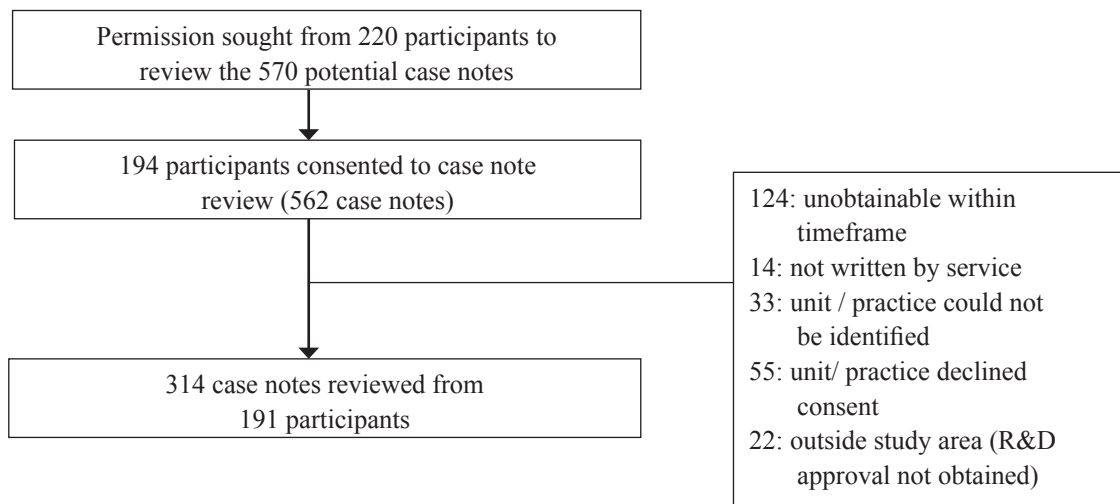
**Figure 3d – Walk-in Centre**



### 3.2.8 Did the urgent care services meet the needs of children less than five years?

Case notes were reviewed to determine the extent to which services were assessing and managing children with fever in an appropriate and timely way, based on the NICE Guideline for Feverish Illness<sup>1</sup> (dataset 2). Information was available from 314 of the 570 potential case notes, representing 191 of the 220 children whose parents agreed access (see Fig. 4). These children were similar to those whose notes were not reviewed (n=145) in terms of age, ethnic mix and socio-economic status, and risk level according to parent (see Appendix 7). The findings are reported below for each standard extracted from the NICE guideline. The results for each 'standard' are reported as a total but where there were sufficient number of case notes available (more than 150 notes for all services), the findings are broken down by service type.

**Fig. 4 Case notes reviewed**



#### Clinical assessment using the NICE 'traffic light' system

None of the 314 case notes documented specifically that they had used the NICE Guideline 'traffic light' system in predicting the risk of serious illness although in 3 cases some reference to the NICE guideline was made. However, individual symptoms and signs from the traffic light system were recorded. Table 8 shows the extent to which services assessed the child for features relating to colour, activity, respiratory signs and symptoms, or hydration status (see Appendix for list of symptoms / signs in each category).

The most consistently recorded feature was activity, with 6/8 services recording this in at least 80% of children (GP 56%, WIC 67%). In contrast, skin colour (pallor, etc.) was the least frequently recorded feature. In the 39% (123) of cases where colour was not explicitly documented by the professionals, six were reported as being “exceptionally pale”, “greyish” or “blue” by the parent. There were 15 occasions where there was no documentation on any of the four features in the child’s notes, all in primary care settings. Using the parent report in these 15 cases, 11 were at intermediate risk, and four were low risk. Overall, 4 of these 15 cases were referred to another service.

**Table 8. Documentation of features by service type.**

	Primary Care						Secondary Care		Total N=314
	GPs N=54	OOHs N=15	WICs N=43	NHSD N=45	Ambulance N=10	Other N=68	EDs N=47	CAUs N=32	
Colour	24 (44%)	11 (73%)	13 (30%)	33 (73%)	8 (80%)	54 (79%)	22 (47%)	26 (81%)	191 (61%)
Activity	30 (56%)	13 (87%)	29 (67%)	38 (84%)	9 (90%)	62 (91%)	46 (98%)	28 (88%)	255 (81%)
Respiratory	36 (67%)	10 (67%)	34 (79%)	30 (91%)	9 (90%)	52 (76%)	44 (94%)	31 (97%)	246 (78%)
Hydration	22 (41%)	10 (67%)	34 (79%)	24 (53%)	5 (50%)	65 (96%)	37 (79%)	31 (97%)	228 (73%)
All features	7 (13%)	7 (47%)	7 (16%)	18 (40%)	5 (50%)	51 (75%)	18 (38%)	20 (63%)	133 (42%)
No features	9 (17%)	2 (13%)	0	3 (7%)	0	1 (1%)	0	0	15 (5%)

*Measurement and recording of vital signs as part of the routine assessment*

There were 241 face to face contacts. Temperature or heart rate was measured and recorded on 90% (216/241) of occasions (Table 9). Heart rate was far less commonly recorded in primary care settings compared to secondary care services.

**Table 9. Documentation of temperature and heart rate by service type.\***

	Primary care					Secondary care		
	GPs N = 53	OOHs N = 3*	WICs N = 43	Ambulance N = 10	Other N = 53	EDs N = 47	CAUs N = 32	Total N = 241
Temperature	34 (64%)	3 (100%)	38 (88%)	8 (80%)	52 (98%)	46 (98%)	32 (100%)	213 (88%)
Heart rate	13 (25%)	0	21 (49%)	8 (80%)	53 (100%)	44 (94%)	32 (100%)	171 (71%)
Both	13 (25%)	0	21 (49%)	6 (60%)	52 (98%)	44 (94%)	32 (100%)	168 (70%)
At least one measure	34 (64%)	3 (100%)	38 (88%)	10 (100%)	53 (100%)	46 (98%)	32 (100%)	216 (90%)

\*Excludes remote assessments

### Triaging of children at low, intermediate and high risk

(‘gold standard’ given in italics)

*Management by remote assessment or by the non-paediatric practitioner: Children whose symptoms or combination of symptoms suggest an **immediately life-threatening illness** referred immediately for emergency medical care by ambulance.*

Only one child (at one point of contact only) had symptoms suggesting an immediately life-threatening illness. The mother called an ambulance herself and the child was taken immediately to the emergency department.

*Management by remote assessment: Children with any ‘red’ features but who are not considered to have an immediately life-threatening illness should be urgently assessed by a healthcare professional in a face-to-face setting within 2 hours.*

Where case notes were reviewed, there were 73 occasions where the child was assessed remotely (i.e. not face to face) by a service and none displayed any red features.

According to the parent report, there were 110 occasions where the child was assessed remotely and in 12 cases was displaying red features. Of these, 4 were referred for and had a face to face assessment within two hours. One was referred for face to face assessment but not within 2 hours and one was referred for a telephone assessment within 2 hours. In the remaining cases, timing could not be determined but all were referred for face to face assessment.

*Management by the non-paediatric practitioner: Children with any ‘red’ features but who are not considered to have an immediately life-threatening illness should be referred urgently to the care of a paediatric specialist.*

According to the case notes, there were 12 children displaying red features but not considered to have an immediately life-threatening illness at time of contact. Four were referred to a paediatric specialist. In the remaining cases, there was a lack of information in the notes to determine whether children had been referred to a paediatrician for assessment or had been sent to a general ED where they may or may not have been assessed by a doctor trained in paediatrics.

*Management by remote assessment: Children with 'amber' but no 'red' features should be assessed by a healthcare professional in a face-to-face setting. The urgency of this assessment should be determined by the clinical judgment of the healthcare professional carrying out the remote assessment.*

According to the case notes, there were 10 occasions where children with amber features were assessed remotely. In 80% (8) of these cases the child was referred for a face to face assessment (according to parent report).

According to the parent report, there were 73 occasions where the child had amber features and was assessed remotely. On 47% (34) of occasions the child was referred for a face to face assessment.

*All settings: Children with 'green' features and none of the 'amber' or 'red' features managed at home with appropriate advice for parents and carers, including advice on when to seek further attention from the healthcare services (safety netting)*

As shown in Table 6, there were 125 occasions where the child was displaying only green features according to health professional report, and in 82 cases the child was discharged or kept at home (according to parent). On 85% (70) of occasions, parents recalled being told when they should seek further attention from healthcare services, 12 % (10) were not told and 2% (2) were not sure.

There were 101 contacts where the child was perceived to be displaying only green features by the parent. Of the 83 discharged or kept at home, 72% (60) of parents recalled being told when they should seek further attention from healthcare services, 24% (20) did not receive advice and 3 (4%) were not sure.

## Children managed at home

*All settings: Following contact with a healthcare professional, parents and carers looking after their **feverish child at home** who are given advice on when to seek further advice.*

According to the case notes, there were 175 occasions when the parent was advised to keep the child at home. On 100 (57%) occasions, there was documentation that the parent was given advice about what to look for to indicate deterioration and on 130 (74%) occasions given advice about who to contact in such an event. This varied considerably by service type (Table 10), but overall documentation of this component was better in primary care than secondary care.

**Table 10: Evidence of safety netting advice being given and recorded in case notes for children sent home.**

	Primary Care						Secondary Care		Total N = 175
	GPs N = 43	OOHs N = 6	WICs N = 32	NHSD N = 21	Ambulance N = 0	Other N = 12	EDs N = 29	CAUs N = 32	
Advice given on what to look for	27 (63%)	4 (67%)	23 (72%)	10 (48%)		11 (92%)	13 (45%)	12 (38%)	100 (57%)
Not given	11	2	6	11		0	11	0	41
Not known	5	0	3	0		1	5	20	34
Advice given on who to contact	29 (67%)	3 (50%)	26 (81%)	19 (90%)		11 (92%)	18 (62%)	24 (75%)	130 (74%)
Not given	9	3	2	2		0	6	0	22
Not known	5	0	4	0		1	5	8	23

### 3.3 Parent and carer perspectives

#### Seeking advice from services

Participants evaluated their own advice seeking behaviour in terms of whether it was appropriate or not, and gave justifications. One parent reflected on the experiences and anxieties of other parents they knew regarding accessing health services for children:

*Do I go to the hospital? What do I do? And, I've had to call somebody like NHS Direct. I think this happens to pretty much most of the people I talk to that have young children. There's a point where you ring your sister, and you ring your mum, and you say: what do I do? What do I do? Am I doing the right thing? We all seem terribly anxious about making the right decisions as regards something like a fever, which can be quite difficult to monitor and manage. Especially if you have a young child that you cannot administer medicine very easily or things like that. So, there does seem to be a contemporary anxiety, perhaps over the top, about what's wrong with our children. (Parent of 4-year-old, 2 contacts, in and out of hours).*

Family and friends were mentioned as a support mechanism by a number of participants, although their role was not likened to that of a health professional.

### **Expectations of services**

Some parents expressed frustration and concerns about the timeliness of the assessment and how long they had to wait for their child to be seen. They felt it wasn't helpful to be sat waiting when the child was not well particularly if it was a young baby. One parent commented that older children are more able to understand why they are waiting, but younger children cannot. Parents had expectations of how quickly they thought their child should be seen. For example, one parent expected to be seen straightaway when she went to the hospital because she had a young baby with a very high temperature. Some parents reported seeking face-to-face contact if they felt that they had been kept waiting too long by an NHS Direct nurse to call them back. Another parent commented that all children should be prioritised and that there should be medical staff on reception to prioritise cases:

*We thought we saw the rash at the walk-in, which actually got me a bit... which got me a bit angry with the walk-in, because it was packed and although I appreciate everyone's there for a reason I could see that there were a few people there who had maybe just got a cold or whatever. And we were in the waiting room under a meningitis poster with a little girl, obviously limp and in distress, who had 5 or 6 of the 13 symptoms listed on there and had to wait for half an hour to see somebody. (Parent of 2-year-old, 2 contacts, in hours.)*

One non-British parent who had called an ambulance due to febrile convulsions stated they would have preferred a home visit by a doctor as in her country of origin:

*It was fine the time before that the ambulance came and we went into the hospital and that way, and I can see that it's a big service to ask for, but when there's such a worry involved I think at least until they are... I don't know I can't say actually it's my first child, but at least until they're three years old and a little stronger I would think the doctor would come and see them. (Parent of 1-year-old, 2 contacts, in and out of hours.)*

Parents also expected their concerns to be taken seriously and to be 'listened to' and not made to feel like a 'panicky' parent. This was particularly the case where the illness was perceived as potentially life-threatening and/or where the child was very distressed. Participants often referred to their experience of their own children, how they could tell if the child's appearance or behaviour differed from usual indicating illness, and how they

got upset if they felt health professionals were either minimising their concerns and/or questioning their ability to care for the child. One parent stated:

*No, I was made to feel as though I was a panicky mother and he really was fine and he probably just had a bit of a temperature and it wasn't a problem. But because I know him quite well obviously, I knew that there was something that was quite wrong, and that was the reason I kept on persisting in trying to get him care..... (Parent of 4-month-old, 6 contacts, in and out of hours.)*

Advice and help varied depending on whom the parent saw or who answered the call, as one parent explained:

*That's a bit hit and miss again. A couple of times they've been very good. Very busy. But very good. And a couple of times not so good. And sort of we've felt a bit ignored and probably just rushed in rushed out and things. But all in all not a too bad experience at all. Some of the staff have been excellent. And then others I think it must have been a bad night and they've been less eager to help and give out advice and things really. (Parent of 3-year-old, 5 contacts, in hours.)*

Several parents gave examples of staff who had provided a high standard of care for their child and had listened carefully to their concerns, explained what was happening and reassured them.

### **Need for appropriate information and advice**

Parents had a range of fever- and service-specific information needs. These included: basic fever management at home (such as keeping the child cool); minor (viral) illnesses in children and when the child needs, for example, antibiotics; 'benign' rashes and those associated with meningitis; the seriousness of symptoms associated with fever; what to do in an emergency and what numbers to call; service opening hours and telephone numbers; how GP appointment systems work; and, why one's own GP cannot always be available. For example, several participants found fast breathing and management of dehydration associated with high temperature alarming.

Parents wanted information and advice about the point at which a child needed to be seen by a health professional for a high temperature alone. One parent verbalised this common concern, also referring to the child's previous illness history:

*I think it [temperature] was just over 38, so obviously with normal temperature and the advice they give you about babies, I just wanted to make sure, how high it would have to be before I would have to take her to see the doctor. So I think it was just over 38, so it was quite high for her; she doesn't tend to have temperatures very often. (Parent of 9-month-old, 1 contact, out of hours.)*

Another parent commented:

*... because we have also NHS book on, I think, up to five year olds healthcare treatment with general guidelines and we did look into that and it was quite unclear how to decide whether the fever is really high, really worrying or it was normal level of fever. (Parent of 26-month-old, 3 contacts, in and out hours.)*

There appeared to be a need for more information on the use and effects of medication. A number of participants also mentioned that they did not know that ibuprofen and paracetamol could be alternated. Participants reported that advice on how to administer medicine to young children can be confusing if not conflicting:

*The only thing I would like to comment on is the fact that there is differing information from different people about the amount of ibuprofen that you give. When you go to hospital, it is very much they give you paracetamol based on his weight, whereas when we discussed this at the Walk-in Centre, because I had not given him paracetamol or ibuprofen since 10.00 pm the previous night, they said it wasn't based on his weight, it was just based on what the recommended dosage is on the bottle, and that's what you are supposed to give, and not any more. That was a bit ambiguous and I thought it should be cleared up really. (Parent of 1-year-old, 3 contacts, in and out of hours.)*

Several participants reported that they had access to the internet and were generally using it for managing the child's health care at home. Participants had looked for information on the internet specifically for fever and rashes prior to contacting services. Yet many stated that the information they found on the internet was either not quite reassuring enough, or encouraged them to contact either NHS Direct or their GP. There also appeared to be a limit as to how much information about illnesses was desirable. Some went into too much depth and parents did not wish to 'scare' themselves unnecessarily. At the same time, many welcomed information leaflets not only about fever but children's illnesses more generally.

None of the participants in this sample mentioned that they had received the patient version of the NICE Guideline for Feverish Illness<sup>1</sup>. One parent commented:

*I've just seen it in passing somewhere, I don't know where it is now. That's great, but you know it's like anything, I was looking for information and if someone had given me that leaflet then that would be great, I would have had it in my handbag. (Parent of 5-month-old, 5 contacts, in hours.)*

## **What works well and what could be improved**

Participants were asked for specific examples of what they felt worked well with the system. Common responses were as follows:

- Telephone advice including on whether face-to-face assessment is required.
- Open access system at hospitals.
- Proximity to OOH surgeries or WICs.
- Health professionals with good listening skills.
- Reassurance and sympathetic communication by professionals that takes into account parental stress at the time of the appointment.

Suggestions for what could be improved included the following:

- Written information about fever management and a high temperature and at what point to seek medical care and from where.
- Information provision about analgesia and antipyretics.
- Clear communication about what the child has or is likely to have, and what signs to look out for.
- Following discharge from a service, explicit indication as to what symptoms to watch for, and what should trigger a return to the service.
- Consistency of all fever management related information provision across the board via correct media.
- Timely assessments and not having to wait for long periods.
- Understanding the specific needs that children and their families may have, such as inconvenience associated with attending face to face services regarding transport, family circumstances or time of the day.

### **3.4 Issues highlighted by health professionals**

An overview of parent's perspectives was presented to health professionals at each of the three sites. Their responses identified the following key issues:

- The evaluation of children with feverish illness should be conducted by health professionals with paediatric training.
- There is a need for separation of children and adults areas.
- There is a need for explicit information and advice for parents (including written advice available via popular websites) on how to manage a febrile child and which telephone services to use and when.
- An emerging issue is recent arrivals / non-English speakers whose knowledge of English or services available may be insufficient to use services appropriately; health professionals felt they required more support with this.

## 4. Discussion

The pilot study has explored the patient journey of a diverse sample through the urgent care system from the parent's perspective with cross validation by case notes. The findings are drawn primarily from retrospective parent accounts and informed by contemporaneous notes made by health care professionals and previous research in relevant areas. Previous recommendations for improvements to services are often 'serious / adverse incident' led. One of the strengths of this study is that it includes a high proportion of children with mild or moderate illness, which reflects the majority of children in the community with febrile illness, and evaluates their complete journey through the system. It builds on previous research on service use, which has tended to focus on one service at a time<sup>14, 16, 20, 21, 22</sup> by exploring the system as a whole.

Feverish illness is one of the most common reasons for parents to seek medical care for their young child<sup>12,15</sup> and can be a cause for much concern. These anxieties may in part relate to the perceived potential harmful effects or seriousness of the fever and high temperature especially if left untreated<sup>15,32,33</sup>, fear about the underlying illness<sup>33</sup>, parental and family factors<sup>14</sup>, demographic factors<sup>34</sup>, and lack of knowledge about fever, the consequences and appropriate treatment<sup>12</sup>. Fever may of course be the harbinger of serious illness, and children can deteriorate very rapidly when septicaemic, for example. The term 'fever phobia' has been used to refer to the unrealistic fears that parents may express about the potential outcome of fever<sup>35</sup>. These anxieties may lead to excessive use of, or place a significant burden on, already overstretched health services<sup>12,22</sup>. In this study, anxieties about meningitis and rash were often reported by participants who were interviewed. One participant reflected on societal changes, suggesting that parents today are increasingly 'nervous'.

Parents had different thresholds for when to seek professional advice with most waiting at least 24 hours from the onset of symptoms. They had differing levels of knowledge and experience of feverish illness in children, and sought information from a range of sources prior to accessing care services including the internet, friends and family. There was a clear view expressed that one reliable, consistent and easily available resource would be valued. We did not fully explore the nature of these sources of information or the sources used specifically by speakers of languages other than English.

## Services used

Despite the plethora of services available, we found that parents were aware of the service options available to them both in and out of hours and appeared to have a hierarchy for their use of services. Parents judged whether to seek advice depending on their personal situation and the specific context for the episode of illness. Even though a whole range of alternative face to face and remote options were available, the majority of parents would most like to see their GP when their child first becomes acutely unwell. Reasons for this included that it was local, convenient, more personal, and that parents thought they would be seen quicker than at other services. When the GP was not available, almost half of the parents in the sample sought initial advice from NHS Direct. This was typically for basic reassurance about thresholds in relation to the point at which a high temperature was considered serious and advice about whether the child needed to be assessed face to face by a doctor. One parent commented: *'I called NHS Direct because I didn't want to waste my GP's time'*. The ambulance service was called on 15 occasions; 9 were because of febrile convulsions. Other reasons given for using particular services were consistent with findings from other research studies and included: the child's age, the perceived severity of the child's illness and need for face-to-face attention; level of parent's knowledge of feverish illness and confidence in how to manage it and prior experience of children's illnesses such as medication; the time of the day; access to transport; and perceived waiting times.

There has been considerable research into the reasons for using Emergency Departments for non-urgent care. Factors influencing use reported in the literature include: being unable to see the primary care provider<sup>14,20</sup>, being referred by reception staff<sup>20</sup>, the perception that their child will be seen more quickly<sup>20</sup>, dissatisfaction with the outcome of the consultation with the previous service<sup>22</sup> and perceived severity of the child's condition<sup>22</sup>. In our sample, approximately half of attendances to the Emergency Department were due to referrals from other services. Only 11% brought their child directly to this service for initial advice. Most attendances (71/83) were for children perceived to be at high or intermediate risk of serious illness by the parent (17 were at intermediate / high risk according to health professionals with 42 not known). One parent commented that they had to access hospital for a minor illness as their primary care provider did not have an interpreter available at the time.

## **Multiple contacts**

The 220 participants used 41 different services a total of 570 times throughout the study period despite the fact that children's illnesses in many cases were relatively short-lived and few were high risk. Previous research on urgent care service use has suggested that parents actively choose services, seek second opinions<sup>13</sup>, 'doctor-shop'<sup>36</sup>, or have too many options available, resulting in inappropriate attendances and over-crowding, particularly at Emergency Departments. Similar concerns were expressed by health professionals during the study workshops about the perceived inappropriate use of in and out of hours services and the 999 service. These reasons were not supported by the findings in the current study. Parents followed a number of different pathways but multiple contacts were not always self directed and many were initiated by the services (221 of the 350 non-first contacts). It is unclear whether these multiple contacts added any clear benefit to the care of the child. This was one parent's experience who felt that the first three of their (six) contacts with services were unnecessary and delayed their child receiving definitive care. Initial contact with NHS Direct led to a higher proportion of further contacts (79%) than for any other service despite only 5% being high risk. This may reflect a lack of training in recognising sick children and making definitive decisions by health professionals. However the case studies illustrate the complexity involved where the child's pathway consists of multiple contacts. We did not identify any common factors influencing or contributing to the multiple contacts in our sample.

## **Seriousness of illness**

We attempted to stratify the level of illness severity by applying the 'traffic light' system in the NICE guideline for Feverish Illness<sup>1</sup> to the history as given by parents, and then sought to validate this by assessing the health professional's assessment. Using this approach, we found that the majority of children included in the study had mild to moderate illness. However when parents gave their child's history, few expressed concerns about symptoms relating to 'colour' and 'activity level'. They did not always use the same language as that of the NICE guideline instead using a variety of terms to describe symptoms, particularly with pallor and child's behaviour making it difficult on occasion to classify the level of risk. Overall, we found low agreement on risk level between parent and health professional report with parents perceiving their child to be sicker than the health professional's assessment.

## **Assessment and triaging**

This study used the NICE guideline for Feverish Illness<sup>1</sup> as a framework. The review of case notes found that none of the services included in this study were using the NICE guideline 'traffic light' system to predict the risk of serious illness, although in three case notes some reference to the guideline was made. However, children were assessed for at least one of the features of the 'traffic light' system in 95% of cases. Symptoms relating to colour were the least well recorded. Most primary care services did not routinely record all of the observations recommended in the NICE guideline and many appeared to only record features if they were relevant to the overall impression / diagnosis of the child's illness. Health professionals at the study workshops reported that the NICE guideline 'traffic light' system was not routinely used as a tool for assessing children instead preferring to use alternative assessment tools such as a local guideline or commonly used triage scheme; it is not known whether these were based on the NICE guideline.

Children at low, high and intermediate risk were appropriately triaged by remote, paediatric and non-paediatric services (where measured) in 79% (83/105) of cases. Children at highest risk of serious illness were referred urgently by non-paediatric practitioners to a paediatric specialist in 4 of 12 cases (8 not known). However, there were insufficient children with life threatening symptoms and incomplete case note reviews to measure whether or not the children with red symptoms were appropriately managed.

## **Safety netting**

The professional's role requires empowering parents to understand and manage their child's illness appropriately, and providing appropriate information tailored to parents' particular needs<sup>37</sup>. Inadequate information given to parents regarding fever management may heighten parent's anxiety<sup>32</sup> and lead to further contacts. The NICE guideline for Feverish Illness<sup>1</sup> recommends that parent and carers looking after their feverish child at home following contact with a health professional should be given advice on when to seek further advice. In this study, of those parents who were sent home or kept their child at home, 81% recalled being given advice on when to seek further help (16% did not and 3% did not know). Where information was recorded in case notes, 57% documented that advice was given about what to look for to indicate deterioration. This was better recorded by primary care services than by secondary care services. Health professionals told us at the study workshops that general advice is given, such as 'come back if you are concerned'. Few parents interviewed recalled being given detailed information,

including 'red flags', i.e. worrying symptoms to watch out for. This may be because the information provided was not given clearly enough. One particular service - a unique team of community children's nurses - was consistent in providing appropriate safety netting and 'red flag' advice, potentially playing a part in allowing quite unwell children to remain at home. This was well received by the parents we spoke to. In addition we found a significant association between being given safety netting advice or not (i.e. told what to do if the child got worse / did not get better) and seeking further contacts. Those who did receive such advice were less likely to seek further advice. However, we did not explore the nature of the safety netting advice and this finding should be interpreted with caution.

## **Expectations**

Parents expected their child to be assessed and treated in a timely manner. However, as our sample involved very few sick children, the concerns expressed in the interviews were less about the need for urgent admissions but more to do with waiting times and inconvenience for young children. Some parents felt they waited too long for an NHS Direct nurse to call them back or endured long waits at the hospital which added to the parent's anxiety. There were suggestions that children should be prioritised over adults particularly as young children are less able to understand why they have to wait and that waiting areas should be appropriate for children. Parents may be more likely to accept the wait and prioritisation of needs if they have more explanation and information about their wait, the system and alternative services, and are not blamed for not knowing about alternative services.<sup>38</sup> Parents wanted to be treated sympathetically and sensitively and have their concerns taken seriously, not be 'judged', or made to feel like a 'panicky' parent. Parents had much praise for services and staff that did treat them in a sensitive and caring manner. Preferences were also expressed for home visits (nurses and GPs) and same day GP appointments. Parents wanted to understand what was meant if they were told that their child's illness was 'viral' and some wanted a 'diagnosis'. Diagnostic uncertainties can leave parents feeling worried and lead to them seeking further advice.<sup>39,40</sup>

## **Need for appropriate information and advice**

A common theme throughout the parents' accounts was a need for reassurance and good consistent information from services about feverish illness, its consequences and treatment - explained in a way that they could understand. Some reported being given conflicting advice about medication. Parents also wanted information about service opening hours and telephone numbers. This is supported by health professionals' views gathered during the research process. Participants expected to receive information and advice that was clearly communicated by service providers, taking into account the fact that it may be difficult for a parent to retain information during an appointment for situational reasons. Accurate information is needed that is widely disseminated through appropriate resources, taking into account factors such as language needs, levels of literacy, and accessibility. It should be targeted at a basic level but signposted to more detailed information for those who want it and have limited parental experience<sup>41</sup>. One parent suggested that basic information could be included in the 'red book. If this had been available, this might have shortened the journeys for some parents<sup>42</sup>. Emotional support via personal communication (e.g. family and friends) is also important alongside mass communication<sup>13</sup> as are health professionals who listen<sup>43</sup>. In this study, none of the parents reported receiving a copy of the patient version of the NICE guideline for Feverish Illness<sup>1</sup>. More needs to be done to ensure that the time and costs involved in developing national guidelines and patient versions are not wasted. There needs to be a conscious effort to implement guidelines by empowering parents and using national guidelines as a framework for health information for parents and carers.

## **Barriers to pathway research**

We experienced a series of delays to recruitment which meant that we missed the peak season for fever. The delays relating to obtaining Research and Development (R&D) approval from collaborating Trusts, and study adoption by UKCRN and the primary care research network (needed to begin recruitment of GP practices) were not justified by any specific ethical risks in any of the participating Trusts / services. In total, 12 R&D submissions had to be made. These required numerous modifications and resubmissions, despite the fact that the study and all associated materials had been approved by the Research Ethics Approval Committee. Added to this, were the delays attendant on obtaining a research passport including needing to obtain a passport for one researcher

who held an NHS contract for the same Health Trust. Overall, it took between 1.5 and 7.5 months to obtain R&D approval from each of these Trusts. Delays were also experienced in gaining co-operation from coroners whose help we needed to check our recruited children against their data to ensure that no children had died between the parents expressing an interest and the telephone survey being conducted. Unfortunately, several coroners refused, resulting in lengthy enquiries through the local records offices.

Further research exploring the whole pathway of care for patients is required to help inform service planning and provision. However researchers wishing to carry out similar work should allow at least six months in order to obtain the necessary approvals, ensure a local champion is identified in each site, researchers to be site based, and allow a longer recruitment period. The centralised system for Research Ethics approval worked extremely well, and if a similar system were in place for the relevant R&D approvals, avoiding multiple submissions of the same data on different application forms, and assessment at different committees, such studies would proceed far quicker.

### **Study strengths and limitations**

This is the first study of the urgent care of children aged less than 5 years examining service provision from the parent's perspective, matched to the professional evaluation, and mapping the pathway of care. It has helped to identify the reasons for using particular services, why some parents have multiple contacts and whether children are being appropriately triaged and managed by services. It has offered some insights into parents' navigation of the system, the number of contacts in acute illness and whether children are being appropriately triaged, as well as into the information needs of parents. However, there were a number of study limitations.

First, there were a number of barriers to obtaining the original target sample. These included: delays in the onset of the study regarding R&D approvals from individual Trusts; delays in the study being adopted by the UKCRN; local barriers for collaborating units to engage participants, for example, due to the outbreak of Swine Flu; and the eventual drop-out rate by parents who were approached. Hence the results should be interpreted as exploratory and indicative.

Second, it was disappointing to note that although all urgent care services were included in the study, no children were recruited through the Ambulance services and our information on the use of this service by parents relies on cases recruited from other primary and secondary services but where the ambulance was used as part of the pathway. This does leave a significant gap in relation to children who may have been assessed by the Ambulance service, but advised by them to stay at home, as they will not have been captured elsewhere.

Finally, although the short telephone questionnaire (dataset 1) included parents who used translation services, none participated in the interviews thus limiting our understanding of their use of services.

## 5. Recommendations

### Implications and actions recommended

Overall, the urgent care services for children aged less than five years appear to be working well for the majority. However, the frequent contacts for short-lived illnesses suggest certain weaknesses in the service. Key recommendations arising from this report include:

- Parents appear to be aware of the services available to them, and their preference for initial advice is the GP. Facilitating such access to the GP is therefore essential. In addition, resources for promoting services should be tailored towards the needs of the local population.
- Parents of children with self-limiting illnesses offered safety netting advice were less likely to use further services. Thus it is essential that safety netting advice is offered to all parents. The advice should be more specific to the child's condition, i.e. what symptoms / signs the parent should look for, and what should prompt a return to the health provider.
- There is an urgent need for explicit, standardised information regarding febrile illnesses in children (what level of fever is a concern, what symptoms should be looked for, what treatment should be given and in what doses, when medical assessment should be sought). This should be provided in writing, with local contact numbers attached. Other mediums should also be considered<sup>7</sup>, for example, for people who cannot read.
- The above should be widely disseminated, through resources that parents use (such as the 'red book', health visitors, parent websites, social networking sites, other media).
- Based on the findings, we recommend all staff dealing with the urgent care of children in both face to face and remote settings are appropriately trained in the assessment of acutely ill children, sensitive to the needs of parents, and skilled in examining / assessing children.
- Most primary care services did not routinely record all of the observations recommended in the NICE guideline for Feverish Illness. Improved recording of symptoms and signs, and the provider's overall impression, would be of value for future audits.

- We found Research & Development (R&D) approval processes unnecessarily repetitive and time consuming, yielding no improvement in research quality or governance, but significantly impeding the progress and adding to the costs of the project. We appreciate improvements are underway and urge that these are subjected to regular scrutiny and audit to ensure that in future approved research is facilitated.
- The findings of the report would lend itself to the development of Patient Reported Experience Measures (PREM) and commissioning tools to ensure that urgent care services are addressing key issues from a parental perspective.
- Following dissemination of the report and tools and provision of appropriate information to parents, a further review of services in 18 months would be of value to estimate the impact (e.g. reduction in contacts, appropriate triaging) and satisfaction with the service provided.
- The triage tool in the NICE guideline for Feverish Illness should be validated in practice to ensure that the recommended triaging of febrile children is effective at discriminating the sick from the well child.
- A more effective strategy is needed to ensure that the public is aware of NICE's information for parents on feverish illness and how to access it.

### **Recommendations for future research**

Further research is also needed on:

- The pathways of the critically ill as they were underrepresented in this study.
- Parental perception versus health professional perception of the severity of the child's illness.
- The content and medium used for dissemination of information regarding febrile illness in children.
- What safety netting advice should consist of.
- The needs of specific groups for urgent care such as recent arrivals to the UK with language needs and other hard to reach groups.
- How health professionals provide information about assessment and management of children and the understanding of parents of this information.

## **6. Conclusion**

This is the first comprehensive study of parents' experiences of urgent care provision for children aged under five years, across all services, with mapping of the pathway of care. In common with the clinical scenarios found in this age group, the majority of children were low or intermediate risk. A number of interesting features are noted, namely that despite the large number of services available to parents both in and out of hours, they are knowledgeable about all the service options, and have a hierarchy for their use of services. It was clear that parents' first choice for urgent care of the sick infant was the GP, when this was not available out of hours, parents usually used other primary care services such as NHS Direct or the Walk-in Centre.

The majority of children had multiple contacts with health care professionals (median 3, range 1-13), despite the low numbers of high risk cases. Contrary to the perceptions of professionals, this was not due to 'doctor shopping', but rather were referrals through the service from one provider to another. Unfortunately, no children were recruited by the ambulance services for this study; therefore our information on the use of this service by parents relies on cases where the ambulance was part of another pathway. Based on this limited information, it appeared that ambulances were only called for children at high risk of serious illness, the majority of whom had had seizures.

Parents used a variety of resources for information on fever / management of feverish illness, although no parent was aware of parental advice provided by NICE. Parents expressed dissatisfaction with the level and consistency of written advice available to them.

Regarding the care given by providers, while the NICE guidance was not referred to directly in the clinical records, most services were recording at least one of the four domains within this, and children at high, intermediate and low risk were being appropriately managed in 79% of cases. Reassuringly, at least 81% of parents recalled being given 'safety netting' advice following their contact.

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## Appendix 1: NICE traffic light system for identifying likelihood of serious illness<sup>1</sup>

	Green – low risk	Amber – intermediate risk	Red – high risk
Colour	Normal colour of skin, lips and tongue	Pallor reported by parent/carer	Pale/mottled/ashen/blue
Activity	Responds normally to social cues Content/smiles Stays awake or awakens quickly Strong normal cry/not crying	Not responding normally to social cues Wakes only with prolonged stimulation Decreased activity No smile	No response to social cues Appears ill to a healthcare professional Unable to rouse or if roused does not stay awake Weak, high-pitched or continuous cry
Respiratory		Nasal flaring Tachypnoea - RR >50 age 6-12 months - RR > 40 age > 12 months Oxygen saturation ≤95% in air Crackles	Grunting Tachypnoea - RR > 60 Moderate or severe chest indrawing
Hydration	Normal skin and eyes Moist mucous membranes	Dry mucous membranes Poor feeding in infants CRT ≥ 3 seconds Reduced urine output	Reduced skin turgor
Other	None of the amber or red symptoms or signs	Fever for ≥ 5 days Swelling of a limb or joint Non weight bearing/not using an extremity A new lump ≥ 2 cm	Age 0-3 months, temperature ≥ 38°C Age 3-6 months, temperature ≥ 39°C Non-blanching rash Bulging fontanelle Neck stiffness Status epilepticus Focal neurological signs Focal seizures Bile-stained vomiting

CRT = capillary refill time    RR = respiratory rate

## Appendix 2: Profile of interviewees

Recruitment Site	Total number of contacts	Time of contact	Child's ethnicity	Child's age at time of first attendance	Deprivation quintile by child population	Urban/ Inner city/ Rural
Hospital	8	IN/OUT	White British	25	61-80%	urban
Hospital	3	IN	Black	18	61-80%	rural
Hospital	5	IN/OUT	White British	16	61-80%	urban
Hospital	2	IN	Asian	22	41-60%	urban
Hospital	2	IN	Asian	36	unmatched	rural
Hospital	4	IN	White British	10	81-100%	rural
Hospital	9	IN/OUT	White British	24	21-40%	urban
Hospital	6	IN/OUT	Mixed	4	61-80%	urban
Hospital	2	IN/OUT	White British	18	41-60%	inner city
Hospital	5	IN/OUT	Asian	13	61-80%	urban
NHS Direct	5	IN/OUT	White British	4	21-40%	inner city
NHS Direct	2	OUT	Mixed	45	0-20%	rural
NHS Direct	1	OUT	Mixed	9	0-20%	inner city
NHS Direct	3	IN/OUT	Mixed	26	0-20%	urban
NHS Direct	3	IN/OUT	White Other	25	61-80%	inner city
Hospital	2	IN	White British	58	21-40%	inner city
NHS Direct	3	IN	Other	12	0-20%	inner city
WIC	1	OUT	White British	25	unmatched	rural
WIC	2	OUT	White British	66	unmatched	urban
GP	1	IN	White British	9	41-60%	urban
WIC	1	OUT	White Other	52	unmatched	urban
WIC	3	IN/OUT	Asian	14	61-80%	urban
WIC	4	IN/OUT	White British	20	81-100%	rural
OOHs	1	IN/OUT	White British	13	81-100%	rural
WIC	5	IN/OUT	White British	23	21-40%	urban
WIC	2	IN	White British	51	41-60%	urban
WIC	2	IN	White British	26	41-60%	urban
WIC	2	IN	White British	50	41-60%	inner city
NHS Direct	5	IN/OUT	White British	31	81-100%	urban

## Appendix 3a: Invitation letter

### INVITATION FOR PARENTS AND CARERS OF YOUNG CHILDREN TO TAKE PART IN RESEARCH

**Aim of the project:**

**To understand and improve the experience of parents and carers who need advice when a child has a fever (high temperature).**

Dear Parent/Carer

We are the researchers for this project and would like to invite you to help with our research into parents' experience of seeking advice for their child who has a fever (high temperature).

This is a common reason for a parent or carer to seek advice from a doctor or nurse. The initial assessment will be very important. The doctor or nurse will need to try to work out why your child is ill and to identify the small number of children who may have a serious illness from the majority whose temperature will have a minor cause. The assessment could take place over the phone, for example with NHS Direct, or at the GP's surgery or A&E department.

The whole experience can be a worrying time for parents and carers and it is important that you know where to get help at the appropriate time, in order to receive the correct care for your child. The research team would like to hear about your experience of the help you received when your child had a fever (high temperature). We would like to know which services you chose to contact in your area, what happened, what care and advice you were given, what worked well and what you think could be improved.

The enclosed information sheet will give you more details and may answer some of your questions. If you would like more information about the project please do not hesitate to contact us (details below). We can assure you that the information you provide will be strictly confidential.

**Your decision about whether or not to take part will not affect your child's treatment, now or in the future.**

***The researchers' contact details are:***

Name:           xx  
Email:  
Telephone:    xx  
Address:       xx

Thank you,

xx

**Information about the care of children younger than five years with a fever can be found in the NICE (National Institute for Clinical Excellence) clinical guideline 'Feverish Illness in Children: Assessment and Initial management of children younger than 5 years'. 2007. There is also an information leaflet for parents, families and carers. These can both be found on the following webpage: <http://www.nice.org.uk/Guidance/CG47>. If you would like a hard copy please contact us.**

## Appendix 3b: Information sheet

### Aim of the Research Project

**To understand and improve the experience of parents and carers who need advice when a child has a fever (high temperature).**

### Information Sheet for Parents and Carers

#### Introduction

*You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. It tells you the purpose of this study and what will happen if you take part. Please ask us about anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part and please talk to family/friends or the Trust Patient Advice and Liaison Service (PALS) about the study if you wish.*

#### **What is the purpose of the study?**

The purpose of the study is to improve our understanding of parents' experiences when their child has a high temperature and they seek help. We want to know whether parents are getting the best advice and care as recommended by the NHS and the National Institute for Clinical Excellence ('Feverish Illness in Children assessment and initial management in children younger than 5 years'). We hope to use this information to improve the services available.

The study is organised by the Royal College of Paediatrics and Child Health (RCPCH) and is supported by the Royal College of General Practitioners and the College of Emergency Medicine. It is being funded by the Department of Health. The person asking you questions will not be any of the doctors or nurses who have looked after your child.

#### **Why have I been chosen?**

We are inviting all parents and carers in this area who have contacted a doctor or nurse to seek advice for their child with a fever (temperature). The study is being carried out over the Winter and Spring period.

#### **Do I have to take part?**

**No.** It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to opt out at any time and without giving a reason. This would not affect the care and treatment your child receives.

#### **What will happen if I take part?**

1. If you are interested in taking part, your name and contact telephone number, and your child's name and date of birth will be given to a researcher employed by the Royal College of Paediatrics and Child Health. Your details will be kept safe and confidential; only the researchers and their supervisor will be able to see this information.
2. The researcher will phone you within seven days of when you contacted the service to introduce him/herself and find out when it would be convenient to phone you to ask a few questions.
3. The researcher will then phone you at the agreed time to ask you a few questions about the care your child had, your child's symptoms and the advice given. This will last about 8-10 minutes. You can stop it at any time for any reason. It will be recorded provided you give your consent, so that the researcher does not need to take any notes. At the end of the telephone call you will be asked for permission to look at your child's medical notes to find out more information. You will also be asked whether you would be interested in taking part in a second telephone call to provide more detailed information.

Please note that the person conducting the telephone questionnaire and interview will not be able to give medical advice.

**What happens next?**

We will be inviting those who are interested in helping us further to be interviewed over the phone about why they chose this particular source of help (NHS Direct/A&E/GP/ etc) and giving more detailed information about what happened and how things could be improved. The researcher will phone you at an agreed time with more detailed questions which will last about 30-40 minutes. Again you can stop it at any time.

**Will my taking part in this study be kept confidential?**

Yes. The phone-call will be recorded with your permission so that our researcher does not have to take notes. All the recordings will be transferred on to a secure computer and written transcripts made and kept for analysis. The recording will then be erased from the recorder. All the information will be anonymised so that no-one taking part can be identified. This information we collect will be put together in the form of a report to help the Department of Health improve the services available. Your child's personal details will not appear. With your consent, we would like to share the results from this with those who have been involved in your child's care and other professionals.

If you have any complaints about the way in which you have been treated during the study, the details of who to contact at RCPCH is given at the end of this letter.

**What are the possible benefits of taking part?**

Your experience will be used to help to improve these services. We want to learn exactly how you felt about things. If you like what happened, it will encourage the NHS to do that more. If you don't like what happened, we can learn from you and try to make improvements.

**Will anything change after the project has finished?**

As a result of the study local services and teams will meet to discuss whether anything should be changed. A summary of the findings can be posted to you.

**What are the possible disadvantages or risks of taking part?**

If you find it difficult and upsetting to talk about your experiences you can stop at any time. If you have a complaint about the way you have been dealt with during the study, our trained researcher will provide you with contact details of the Patient Advice and Liaison Service who will advise you on what to do next.

**How do I consent?**

If you are interested in taking part and have understood the information provided please sign the enclosed consent form and post it back in the self addressed envelope. Please be assured that your child's treatment will not be affected in any way, whether you choose to take part or not.

<b>For further information, please contact our Researchers, xx</b>	
Address:	xx
Telephone:	xx
Email:	xx

<b>For independent advice, please contact xx</b>	
Address:	xx
Telephone:	xx
Email:	xx

**Thank you for taking the time to read this.**

## Appendix 3c: Consent for parents

Participant identification number:

### PARTICIPANT CONSENT FORM

**To understand and improve the experience of parents and carers who need advice when a child has a fever (high temperature).**

Name of Researcher: xx

**Please tick the boxes if you agree**

- I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my child's medical care or legal rights being affected.
- I agree to the tape-recording of the telephone questionnaire and interview.
- I agree to my child's medical records being looked at by the researcher.
- I agree to take part in the above study.

Please sign here: \_\_\_\_\_ Date \_\_\_\_\_

Please print your name clearly in capitals: \_\_\_\_\_

**Thank you.**

Please hand this form in to a member of staff or send it back to the researcher using the stamped addressed envelope.

# Appendix 4: Parent questionnaire

Date       ID no:     Sheet no.  Of

Royal College of Paediatrics and Child Health and partners

## Parent Telephone Questionnaire (8-10 minutes)

- INTRODUCE SELF.
- EXPLAIN STUDY AND PURPOSE OF QUESTIONNAIRE.
- EXPLAIN ABOUT CONFIDENTIALITY AND RECORDING
- TAKE VERBAL INFORMED CONSENT

<input type="checkbox"/> Informed consent obtained for questionnaire																			
<input type="checkbox"/> Informed consent not obtained. Any comments: .....																			
<b>Section A: Childs' details:</b> Firstly, please tell me a bit about your child:																			
1.	Is your child a girl or boy? <span style="float: right;">Girl / Boy</span>																		
2.	What is his or her date of birth? <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>																		
3.	Which postcode do you live in?																		
4.	<p>Can you clarify your child's ethnic origin please for example, White British, Black Afro-Caribbean?</p> <table style="width: 100%;"> <tr> <td><input type="checkbox"/> White British</td> <td><input type="checkbox"/> Bangladeshi</td> </tr> <tr> <td><input type="checkbox"/> White other (state) ...</td> <td><input type="checkbox"/> Asian (other): .....</td> </tr> <tr> <td><input type="checkbox"/> White Irish ...</td> <td><input type="checkbox"/> Caribbean</td> </tr> <tr> <td><input type="checkbox"/> White and Black Caribbean</td> <td><input type="checkbox"/> African</td> </tr> <tr> <td><input type="checkbox"/> White and Black African</td> <td><input type="checkbox"/> Black (other) .....</td> </tr> <tr> <td><input type="checkbox"/> White and Asian</td> <td><input type="checkbox"/> Chinese</td> </tr> <tr> <td><input type="checkbox"/> Mixed (other) .....</td> <td><input type="checkbox"/> Other (state): .....</td> </tr> <tr> <td><input type="checkbox"/> Indian</td> <td><input type="checkbox"/> Does not wish to say</td> </tr> <tr> <td><input type="checkbox"/> Pakistani</td> <td></td> </tr> </table>	<input type="checkbox"/> White British	<input type="checkbox"/> Bangladeshi	<input type="checkbox"/> White other (state) ...	<input type="checkbox"/> Asian (other): .....	<input type="checkbox"/> White Irish ...	<input type="checkbox"/> Caribbean	<input type="checkbox"/> White and Black Caribbean	<input type="checkbox"/> African	<input type="checkbox"/> White and Black African	<input type="checkbox"/> Black (other) .....	<input type="checkbox"/> White and Asian	<input type="checkbox"/> Chinese	<input type="checkbox"/> Mixed (other) .....	<input type="checkbox"/> Other (state): .....	<input type="checkbox"/> Indian	<input type="checkbox"/> Does not wish to say	<input type="checkbox"/> Pakistani	
<input type="checkbox"/> White British	<input type="checkbox"/> Bangladeshi																		
<input type="checkbox"/> White other (state) ...	<input type="checkbox"/> Asian (other): .....																		
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<input type="checkbox"/> Mixed (other) .....	<input type="checkbox"/> Other (state): .....																		
<input type="checkbox"/> Indian	<input type="checkbox"/> Does not wish to say																		
<input type="checkbox"/> Pakistani																			
<b>Section B: Contacts</b>																			
5.1	Did you see or speak to anyone else other than [service type first contacted]? <span style="float: right;">Y / N / NK</span>																		
5.2	If yes, did they give health advice? If no, GO TO NEXT QUESTION <span style="float: right;">Y / N / NK</span>																		
5.3	Which service was this and when was it? <table style="width: 100%;"> <tr> <td><input type="checkbox"/> GP own surgery in person</td> <td><input type="checkbox"/> Walk-in Centre</td> </tr> <tr> <td><input type="checkbox"/> GP own surgery telephone consultation (state whether GP, nurse or receptionist) .....</td> <td><input type="checkbox"/> Called ambulance and treated at home</td> </tr> <tr> <td><input type="checkbox"/> GP out of hours service (telephone/ drop-in)</td> <td><input type="checkbox"/> Called ambulance and taken to hospital</td> </tr> <tr> <td><input type="checkbox"/> GP out of hours service (referred to Urgent Care Centre)</td> <td><input type="checkbox"/> Health visitor</td> </tr> <tr> <td><input type="checkbox"/> NHS Direct by telephone</td> <td><input type="checkbox"/> Local pharmacist</td> </tr> <tr> <td><input type="checkbox"/> NHS Direct online</td> <td><input type="checkbox"/> A&amp;E</td> </tr> <tr> <td><input type="checkbox"/> Other (describe) .....</td> <td></td> </tr> </table>	<input type="checkbox"/> GP own surgery in person	<input type="checkbox"/> Walk-in Centre	<input type="checkbox"/> GP own surgery telephone consultation (state whether GP, nurse or receptionist) .....	<input type="checkbox"/> Called ambulance and treated at home	<input type="checkbox"/> GP out of hours service (telephone/ drop-in)	<input type="checkbox"/> Called ambulance and taken to hospital	<input type="checkbox"/> GP out of hours service (referred to Urgent Care Centre)	<input type="checkbox"/> Health visitor	<input type="checkbox"/> NHS Direct by telephone	<input type="checkbox"/> Local pharmacist	<input type="checkbox"/> NHS Direct online	<input type="checkbox"/> A&E	<input type="checkbox"/> Other (describe) .....					
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<input type="checkbox"/> Other (describe) .....																			
5.4	Day (circle one): Mon / Tues / Wed / Thurs / Fri / Sat / Sun Date: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Time (24 hr clock): <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>																		
5.5	Did you actually see a doctor or nurse? <span style="float: right;">Y / N / NK</span>																		
6	How long had your child been ill before you rang or saw the doctor or nurse (days/ hours)?																		

7	Did your child look more ill than usual?	Y / N / NK
8	What was worrying you most about your child at the time?	
9.1	<p>Did your child look very pale or flushed to you?</p> <p>Green  <input type="checkbox"/> Normal</p> <p>Amber  <input type="checkbox"/> Pale / flushed</p> <p>Red  <input type="checkbox"/> Very pale / blue</p>	
9.2	Was the colour different to normal?	Y / N / NK
9.3	Was he/she behaving as he/she would normally?	Y / N / NK
9.4	<p>If no, was he /she:</p> <p><input type="checkbox"/> Quiet / sleepy / crying quite a lot/wanted to be cuddled more than usual (AMBER)</p> <p><input type="checkbox"/> Not reacting to anyone's face or voice (RED)</p> <p><input type="checkbox"/> Irritable, unable to settle (RED)</p>	
9.5	Was he/she breathing as he/she would normally?	Y / N / NK
9.6	<p>If no, was there:</p> <p><input type="checkbox"/> Noisy or fast breathing (AMBER)</p> <p><input type="checkbox"/> A lot of difficulty in breathing (RED)</p>	
9.7	Other relevant information	
10	Did your child feel hot to you compared to normal?	Y / N / NK
11	<p>What were you told to do next?</p> <p><input type="checkbox"/> Admitted to hospital (state where)</p> <p><input type="checkbox"/> Discharged home GO TO Q12</p> <p><input type="checkbox"/> Sent to A&amp;E</p> <p><input type="checkbox"/> Parent sought another opinion same day</p> <p><input type="checkbox"/> Parent sought another opinion subsequently</p>	
12	<p>IF DISCHARGED FROM HEALTH CARE:</p> <p>Did someone tell you what to do if your child got worse/ there was a change/ doesn't get better</p>	Y / N / NK
13	Did you see or speak to anyone else about your child's illness?	Y / N / NK
<b>IF YES, REPEAT SECTION B</b>		

THANK PARTICIPANT AND ASK IF ANY QUESTIONS  
RE-ASSURE RE CONFIDENTIALITY

<p><b>We would also like to review your child's medical notes for each service they were seen in. Would you give us permission to do so?</b></p>	Y / N / NK
<p><b>If yes, which services do we need to contact?</b></p>	
<p>We are going to do more in-depth interviews so we can understand how services are working and what improvements should be made. It will take 20 minutes. Would you like to help us with this?</p>	Y / N / NK

THANK YOU

## **Appendix 5: Topic Guide**

### **TOPIC GUIDE**

1. Reasons for choosing particular services in and out of hours and expectations of services
2. Experiences of each encounter with an urgent care service and conclusion of each health encounter
3. Whether advice given by services is followed and if not why not
4. Parent perceptions of navigating through the health system over time and how service providers facilitate the child's journey along the care pathway and any interface issues/ barriers to the movement of the child through the care pathway.
5. Examples of what works well and what can be improved
6. Use of NICE guideline

## Appendix 6: Case note proformas

Date       ID no:     Sheet no.  Of

Royal College of Paediatrics and Child Health and partners

### Hospital services - case note review

Emergency Department  Hospital Ward / Assessment unit

1.	When was the contact first made to this service regarding the most recent/current illness?  Day (circle one): Mon / Tues / Wed / Thurs / Fri / Sat / Sun  Date: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Time (24 hr clock): <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>																											
2.	Were there prior contacts with the Health Service? If so, please list each plus date if known (continue on separate sheet if many)																											
3.	Were the following features documented on examination?																											
3.1	<b>COLOUR:</b> <input type="checkbox"/> Normal colour of skin, lips & tongue (GREEN) <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Pallor reported by parent/carer (AMBER) <input type="checkbox"/> Documented within 15 minutes of arrival <input type="checkbox"/> Pale/mottled/ashen/blue (RED)																											
3.2	<b>ACTIVITY:</b> <table style="width: 100%; border: none;"> <tr> <td style="width: 33%;">Green</td> <td style="width: 33%;">Amber</td> <td style="width: 33%;">Red</td> </tr> <tr> <td><input type="checkbox"/> Responds normally to social cues</td> <td><input type="checkbox"/> Not responding normally to social cues</td> <td><input type="checkbox"/> No response to social cues</td> </tr> <tr> <td><input type="checkbox"/> Stays awake or awakens quickly</td> <td><input type="checkbox"/> Wakes only with prolonged stimulation</td> <td><input type="checkbox"/> Does not wake or if roused does not stay awake</td> </tr> <tr> <td><input type="checkbox"/> Content/smiles "alert &amp; orientated"</td> <td><input type="checkbox"/> No smile</td> <td><input type="checkbox"/> Weak, high-pitched or continuous cry</td> </tr> <tr> <td><input type="checkbox"/> Strong normal cry/not crying</td> <td><input type="checkbox"/> Decreased activity</td> <td><input type="checkbox"/> Appears ill to a healthcare professional</td> </tr> <tr> <td colspan="3"><input type="checkbox"/> No information recorded on this feature</td> </tr> </table>	Green	Amber	Red	<input type="checkbox"/> Responds normally to social cues	<input type="checkbox"/> Not responding normally to social cues	<input type="checkbox"/> No response to social cues	<input type="checkbox"/> Stays awake or awakens quickly	<input type="checkbox"/> Wakes only with prolonged stimulation	<input type="checkbox"/> Does not wake or if roused does not stay awake	<input type="checkbox"/> Content/smiles "alert & orientated"	<input type="checkbox"/> No smile	<input type="checkbox"/> Weak, high-pitched or continuous cry	<input type="checkbox"/> Strong normal cry/not crying	<input type="checkbox"/> Decreased activity	<input type="checkbox"/> Appears ill to a healthcare professional	<input type="checkbox"/> No information recorded on this feature											
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3.4	<b>HYDRATION:</b> <table style="width: 100%; border: none;"> <tr> <td style="width: 33%;">Green</td> <td style="width: 33%;">Amber</td> <td style="width: 33%;">Red</td> </tr> <tr> <td><input type="checkbox"/> Normal skin and eyes</td> <td><input type="checkbox"/> Dry mucous membranes</td> <td><input type="checkbox"/> Reduced skin turgor</td> </tr> </table>	Green	Amber	Red	<input type="checkbox"/> Normal skin and eyes	<input type="checkbox"/> Dry mucous membranes	<input type="checkbox"/> Reduced skin turgor																					
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	<input type="checkbox"/> Moist mucous membranes <input type="checkbox"/> CRT < 2 seconds <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Documented within 15 minutes of arrival	<input type="checkbox"/> Poor feeding in infants <input type="checkbox"/> CRT ≥ 3 seconds <input type="checkbox"/> Reduced urine output
3.5	<b>TEMPERATURE:</b> Green <input type="checkbox"/> Age 0-3 months, temperature <38C <input type="checkbox"/> Age 3-6 months, temperature <39C <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Documented within 15 minutes of arrival	<b>PRECISE TEMPERATURE:</b> Amber <input type="checkbox"/> Fever for ≥ 5 days Red <input type="checkbox"/> Age 0–3 mths, temperature ≥ 38°C <input type="checkbox"/> Age 3–6 mths, temperature ≥ 39°C
3.6	<b>HEART RATE:</b> <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Documented	
4	What happened to the child at the end of the assessment? <input type="checkbox"/> Admitted to paediatric ward (state where) <input type="checkbox"/> Discharged home no follow-up <input type="checkbox"/> Discharged home with follow-up (eg GP, paed, HV, ward review, ED clinic, OPA) <input type="checkbox"/> Rapid access clinic <input type="checkbox"/> Children's Day Care Unit <input type="checkbox"/> Referred elsewhere (state where): ..... <input type="checkbox"/> Sent home	
5	Why was the child referred/admitted? <input type="checkbox"/> Further assessment by paediatricians (if Emergency Department patient) <input type="checkbox"/> 4 hour target expiring <input type="checkbox"/> Second expert opinion (e.g. Out-patient appointment or specialist paediatrician) <input type="checkbox"/> For ongoing management (e.g. IV fluids or antibiotics, observation) <input type="checkbox"/> Other (state): .....	
6	<b>If sent home:</b> a) Was advice given about what symptoms and signs to look out for, to indicate deterioration? Y / N / NK b) Was advice given about whom to contact in the event of deterioration? Y / N / NK	
7	Was a consultant involved in the child's care? Y / N / NK	
8	Was the child referred urgently to a paediatric trained specialist (includes PEM trained ED registrars / consultants)? Y / N / NK	
9	If so what was the time interval before the assessment took place?	
10	Was any reference made to the traffic lights in the NICE guideline for Feverish Illness? Y / N / NK	
11	Did the practitioner making the first assessment have some paediatric training? Y / N / NK	
<b>Other relevant information</b>		

NK= not known; ED=Emergency Department

Date

ID no:

Sheet no.  Of

Royal College of Paediatrics and Child Health and partners  
**Non-hospital settings case note review**

UNIT NAME																														
1.	When was the first contact related to this current / most recent illness?  Day (circle one): Mon / Tues / Wed / Thurs / Fri / Sat / Sun  Date: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Time (24 hr clock): <input type="text"/> <input type="text"/> <input type="text"/>																													
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<input type="checkbox"/> No information recorded on this feature																														
<input type="checkbox"/> Documented within 15 minutes of arrival																														
3.4	<b>HYDRATION:</b> <table style="width: 100%; border: none;"> <tr> <td style="width: 33%;">Green</td> <td style="width: 33%;">Amber</td> <td style="width: 33%;">Red</td> </tr> <tr> <td><input type="checkbox"/> Normal skin and eyes</td> <td><input type="checkbox"/> Dry mucous membranes</td> <td><input type="checkbox"/> Reduced skin turgor</td> </tr> </table>			Green	Amber	Red	<input type="checkbox"/> Normal skin and eyes	<input type="checkbox"/> Dry mucous membranes	<input type="checkbox"/> Reduced skin turgor																					
Green	Amber	Red																												
<input type="checkbox"/> Normal skin and eyes	<input type="checkbox"/> Dry mucous membranes	<input type="checkbox"/> Reduced skin turgor																												

	<input type="checkbox"/> Moist mucous membranes <input type="checkbox"/> CRT < 2 seconds <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Documented within 15 minutes of arrival	<input type="checkbox"/> Poor feeding in infants <input type="checkbox"/> CRT ≥ 3 seconds <input type="checkbox"/> Reduced urine output
3.5	<b>TEMPERATURE:</b> Green <input type="checkbox"/> Age 0-3 months, temperature <38C <input type="checkbox"/> Age 3-6 months, temperature <39C <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Documented within 15 minutes of arrival	
	Amber <input type="checkbox"/> Fever for ≥ 5 days	
	Red <input type="checkbox"/> Age 0–3 mths, temperature ≥ 38°C <input type="checkbox"/> Age 3–6 mths, temperature ≥ 39°C	
3.6	<b>HEART RATE:</b> <input type="checkbox"/> No information recorded on this feature <input type="checkbox"/> Documented	
4	What happened to the child at the end of the assessment? <input type="checkbox"/> Admitted (state where) <input type="checkbox"/> Taken to children's admission ward <input type="checkbox"/> Taken to A&E <input type="checkbox"/> Kept at home.      If so, was there follow-up (eg GP, paed, HV, ward review, ED clinic, OPA)?      Y / N / NK <input type="checkbox"/> Sent home <input type="checkbox"/> Other (provide details): .....	
5	Why was the child referred/admitted? <input type="checkbox"/> Further assessment by paediatricians (if Emergency Department patient) <input type="checkbox"/> 4 hour target expiring <input type="checkbox"/> Second expert opinion (e.g. Out-patient appointment or specialist paediatrician) <input type="checkbox"/> For ongoing management (e.g. IV fluids or antibiotics, observation) <input type="checkbox"/> Other (state): .....	
6	<b>If sent or kept at home:</b> a) Was advice given about what symptoms and signs to look out for, to indicate deterioration?      Y / N / NK b) Was advice given about whom to contact in the event of deterioration?      Y / N / NK	
7	How many assessments were there (e.g. first responder, paramedic, ECP)?	
8	Was the child referred urgently to hospital?      Y / N / NK	
9	If so what was the time interval before the assessment took place?	
10	Was any reference made to the traffic lights in the NICE guideline for Feverish Illness?      Y / N / NK	
<b>Other relevant information:</b>		

NK=Not known

## Appendix 7: Case notes reviewed and not reviewed

	<b>Case notes reviewed 314</b>	<b>Case notes not reviewed 256</b>
Number of children	191 cases	145 cases
<i>Child's level of risk according to parent</i>		
High Risk	42	38
Intermediate Risk	187	161
Low Risk	52	49
Not known	33	8
Mean age of child (range)	26 mths (1-71 mths)	24 mths (1-71 mths)
<i>Ethnicity of child</i>		
White British	131 (69%)	90 (62%)
White Other	1 (1%)	1 (1%)
Mixed	14 (7%)	16 (11%)
Asian	22 (12%)	18 (12%)
Black	12 (6%)	7 (5%)
Other	10 (5%)	11(8%)
Unknown	1 (1%)	2 (1%)
<i>Deprivation rank</i>		
0-20% (most deprived)	37 (19%)	25 (17%)
21-40%	33 (17%)	23 (16%)
41-60%	29 (15%)	20 (14%)
61-80%	35 (18%)	28 (19%)
81-100% (least deprived)	40 (21%)	31 (21%)
Unknown	17 (9%)	18 (12%)

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