



The use of primary and secondary care services by children and young people following contact with NHS 111 - investigating the experience and patient flow of four common conditions

Collaborators:



Funded by:



Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

The use of primary and secondary care services by children and young people following contact with NHS 111 – investigating the patient experience and flow for four common conditions

A report by:

Sarah-Ann Burger, Dougal Hargreaves, Ian Maconochie, Andreas Magusin, Karina Pall, Rebecca Pope, Adam Steventon, Amy Tallett, Emily Walton, Arne Wolters

Acknowledgements:

Association of Young People's Health, GOSH Patient and Public Involvement and Patient Experience Team and GOSH Young Persons Forum, INVOLVE, Newcastle University Evaluation Partner, North East London Commissioning Support Unit, North West London champions, North West London in Collaboration for Leadership in Applied Health Research and Care, RCPCH & Us, Together for Short Lives.

This project was funded by NHS England.

Collaborators:

The Health Foundation led on the data linkage and evaluation described in Part 1. The Health Foundation is an independent charity committed to bringing about better health and healthcare for people in the UK. *Our* aim is a healthier population, supported by high-quality healthcare that can be equitably accessed. From giving grants to those working at the front line to carrying out research and policy analysis, *we* shine a light on how to make successful change happen. *We* use what *we* know works on the ground to inform effective policymaking and vice versa. *We* believe good health and healthcare are key to a flourishing society. Through sharing what *we* learn, collaborating with others and building people's skills and knowledge, *we* aim to make a difference and contribute to a healthier population.

Picker Institute Europe led on the development and implementation of the patient reported experience measure of Part 2. The Picker Institute is an international charity working across health and social care. Established in 2000, the organisation continues to have a significant impact in the field of person and family centred care. *We* use people's experiences of health and social care to identify priorities in delivering the highest care quality. *We* measure experiences to uncover incidences of excellent and poor care delivery. *We* work across health and social care systems to support organisations to improve the quality of care.

Paediatricians from **Imperial College NHS Healthcare Trust** and **University College London Hospital** provided the clinical expertise of the three work packages.

Foreword

This report is a product of collaboration between a number of organisations who are dedicated to improving health services. This particular project has a focus on urgent and emergency care in relation to children and young people, and has emerged as one of the projects undertaken during the second phase of the NHS 111 Learning and Development Programme. The collaborators have demonstrated the value of partnership working making full use of the expertise of the participating organisations in conjunction with the NHS.

I have been fortunate to have been involved in the development of urgent and emergency care over the last few years, working with providers and commissioners across England. I have also chaired numerous review panels examining individual cases that have touched the urgent care system highlighting opportunities for service improvement. The work that has been led by the Royal College of Paediatrics and Child Health under the expertise of Dr Ian Maconochie and project management by Karina Pall, along with partners from The Health Foundation, Imperial College Healthcare NHS Trust, Picker Institute Europe, North East London Commissioning Support Unit and a number of NHS services, will help the NHS identify changes that will help improve the care of patients.

The urgent and emergency care system can be complex for patients, their families and carers. NHS England and the Clinical Commissioning Groups are currently embarking on a period of change in urgent and emergency care. Sir Bruce Keogh and Professor Keith Willet have presented NHS England's future vision for urgent and emergency care in '*Transforming Urgent and Emergency Care Services in England: Urgent and Emergency Care Review End of Phase 1 Report*'. The NHS with the public and other partners are now developing Urgent and Emergency Care Networks to implement the findings. NHS England has also recently issued commissioning guidance for integrated urgent care, which will be influenced by this evaluation especially in relation to NHS 111. The Five-Year Forward View sets out how the health service needs to change, and this evaluation provides recommendations for the future that support that vision of promoting wellbeing and preventing ill-health.

The first phase of this service evaluation had a focus on children under the age of five with fever. It provided the NHS with an understanding of the prevalence within the population and the type of services involved in managing this case load. It provided an opportunity to safely link data between primary care, urgent care and acute services. The evaluators were able to develop methodology that enabled a review of diagnosis and management of the target case load as well as a Delphi exercise to seek expert and specialist opinion on the delivery of care. This second phase of evaluation has made considerable gains in understanding the factors that influence patient care, the way in which services are utilised and the use of technical links and informatics to achieve these.

As the NHS starts evolving urgent and emergency care services, this evaluation and the system-wide learning that it has generated will become increasingly more crucial as commissioners and providers make better use of data linkage to improve services and to deliver better patient care.

I am grateful to all the children, young people, their families and their carers involved in this project and for their help in improving our health system. I hope that this evaluation continues to stimulate change in services and provides inspiration for those involved in commissioning and delivering urgent care services for children and young people.

**Dr Sam Shah BDS(Lon) MSc(Lon) MFDS RCS(Eng) MRCPS(Glasg) DLSHTM MFMLM GDLaw PGCert
FDS RCS FFPH
Clinical Lead, NHS 111 Learning and Development Programme
Head of Evaluation and Research, Digital Technology and Urgent Care, NHS England**

Contents

Executive summary	4
Introduction	6
Part 1: Data linkage	10
Aims.....	10
Feasibility of data linkage	10
Methods.....	10
Results.....	11
Implementation of data linkage.....	13
Results.....	13
Part 1: Conclusions	18
Part 2: Patient Reported Experience Measure (PREM) for NHS 111	19
Aims.....	19
Feasibility of PREM development	19
Methods.....	19
Implementation of the PREM.....	22
Methods.....	22
Results.....	23
Part 2: Conclusions	29
Part 3: Online survey.....	30
Aims.....	30
Survey development	30
Methods.....	30
Implementation of the survey	31
Results.....	31
Part 3: Conclusions	33
Discussion.....	34
Recommendations.....	36
Part 1: Data linkage	36
Part 2: PREM.....	36
Part 3: Online survey	37
References.....	38
Appendix 1 - NICE guidelines.....	41
Appendix 2 - Picker frequency tables.....	42
Appendix 3 - Survey validation.....	43
Appendix 4 - CYP and parents and carers online survey.....	44

Executive summary

The Royal College of Paediatrics and Child Health (RCPCH), NHS England, Imperial College NHS Healthcare Trust, The Health Foundation and the Picker Institute Europe collaborated for a project to investigate the NHS 111 service for children and young people (CYP) in North West London.

The demand for urgent care is increasing and there is particular concern for the strain on primary and secondary care services. The strain on primary care services to meet the demands for CYP outside of regular working hours continues to rise, while an increasing number of CYP present to emergency departments with conditions that could be treated within primary care. Parents and carers are often unaware of what local emergency or urgent care services are available and which services are the most appropriate for their child's urgent care needs.

The NHS 111 service was introduced to increase efficiency in directing people to help service users identify the most appropriate urgent care service. Parents, carers and CYP are amongst the highest users of urgent care services and to effectively manage the flow of paediatric patients through primary and secondary care services requires investigation into both the patient journey and experience of parents and carers following the NHS 111 call.

This project was successful as one of a series of studies to receive funding from NHS England for the second phase of the NHS 111 Learning and Development Programme of work (NHS 111 LDP). The NHS 111 LDP sent out a call for proposals in December 2014 for work on topics that have the potential to improve patient care and/or optimise utilisation of the service.

The objectives set in the successful proposal submitted were:

- to investigate the feasibility of linking NHS 111 data with wider NHS administrative data at the person level to understand the predictors of healthcare utilisation following advice from NHS 111
- to identify records of parents and carers who call NHS 111 about their child then utilise other NHS services during that same illness
- to understand how parents and carers use NHS 111, their experience of the call and their actions as a result of calling
- to identify how feedback from parents and carers can be used to improve the service for the future.

The project focuses on four specific conditions; fever, diarrhoea and vomiting, breathlessness and constipation. These were chosen as they are common childhood conditions and have a range of presentations. The first three may have mild, moderate or severe states, and so may require a range of different responses by urgent and emergency services. Constipation may only very rarely present with a life threatening state and can usually be managed in primary care. These conditions therefore cover a spectrum of presentations that may need different services to assist with improving the CYP's condition. In addition, all four conditions are associated with national clinical guidelines to assist with their management.

This project proposed three discrete yet complementary work packages, which are presented in Parts 1-3 of this report. Part 1 assesses the flow of CYP from NHS 111 through to primary and/or secondary care services. This part of the report demonstrates the feasibility of linking NHS 111

data with GP out-of-hours (GP OOH) and Secondary Uses Service (SUS) data, and provides an overview of the challenges, barriers and practicalities in undertaking this work. Analysis of the linked data sets produced information about which health services patients used following the NHS 111 calls. Only a small percentage of CYP calling for the four selected conditions were directed by the NHS 111 health advisors to go to the Emergency Department (ED) (1.1%). ED attendance was relatively uncommon with 7.2% of all callers attending within three hours of the NHS 111 call. Out of those patients who attended ED following the NHS 111 call, the vast majority (over 95%) had been advised by NHS 111 to make a follow up appointment with their GP instead of immediately going to the ED. Further work could investigate the feasibility of adding data on GP services to map more of the healthcare system.

Qualitative work is important to identify why parents and carers do not always appear to follow the advice by NHS 111 and to help make pathways of care more effective and 'user friendly' to parents, carers and CYP (Part 2 of this report, led by the Picker Institute Europe). To understand the parental decision processes and experiences of using the NHS 111 service, the feasibility of developing a Patient Reported Experience Measure (PREM) was explored. The PREM which was developed was implemented using a telephone methodology. The new parent and carer questionnaire functioned well in enabling respondents to report their experience of using NHS 111, highlighting that it is feasible to develop and validate a PREM specific to the NHS 111 service. Further, overall positive experiences of the calls to NHS 111 were associated with parents and carers agreeing with the advice they received (83%), and that subsequently they tended to follow that advice (91%). Further work could evaluate the experience of the complete care pathway of the CYP, from the time of the NHS 111 phone call to the resolution of their condition.

The confidence around access and trust in medical advice for parents and carers in relation to their CYP urgent care was explored using a population-based sample by means of an online survey (Part 3, led by Dr Hargreaves, Research Lead). This work package showed that it was feasible to devise an online survey but the results importantly showed a limited number of responses and the interpretation of the survey would benefit from larger more rigorously tested samples. Further work will look to engage with CYP from the early stages of protocol development to understand the 'pull factors' associated with CYP survey completion.

Future work could explore extending the data linkage work to include a greater range of healthcare services with the ambition of charting the patient journey from the initial NHS 111 call to the last contact point with the NHS in relation to the illness that gave rise to the involvement of NHS 111. The PREM could be incorporated into an extended analysis aimed at understanding the ways in which the perceptions and thoughts of parents and carers influence their use of healthcare services for their child's care. This qualitative work could also continue the online survey, by extending the range of parents, carers and CYP who can take part.

Introduction

This report describes the feasibility and implementation of three work packages commissioned by the NHS 111 Learning and Development Programme Phase 2 (NHS 111 LDP). The remit of the NHS 111 LDP was to investigate:

- *Service improvements that provide more personalised services to support the diverse needs of people using the NHS 111 service*
- *The delivery of technical and informatics enhancements to the NHS 111 service, in particular those that improve integration across the healthcare service.*

The three work packages outlined in this report inform the work of the NHS 111 LDP by investigating CYP's and parents' and carers' experience of using NHS 111 for common paediatric presentations and by providing an analysis of the utilisation of other NHS services following the NHS 111 calls.

Urgent care

The demand for urgent care is steadily growing and the providers in place to support patients with urgent care requirements include General Practice (GP), Ambulance Services, Urgent Care Centres, Walk-in-Centres and Minor Injury Units as well as NHS 111 and Emergency Departments (EDs). The use of these services has become a focus of health services research particularly in relation to the diverse needs of service users and the appropriate use of services (NHS England 2013).

Year on year, more children have been presenting to EDs in England, with approximately 20% more paediatric attendances in 2014 than a decade ago (HSCIC 2014). Almost a quarter of all ED attendances are for people aged under 16 years, with four million paediatric presentations to EDs in England and Wales occurring in 2012 (College of Emergency Medicine 2013 and Department of Health 2012).

Using a conservative definition of 'inappropriate attendance' as applied to a national ED dataset revealed the highest numbers of attendances to lie within the under-16 age group (15%), with a peak in early childhood (McHale 2013). The 'inappropriate attendance' was defined as patients who self-refer with low urgency problems that are unlikely to require admission and are more suitable for other services, such as primary care, telephone advice helplines or pharmacy. In most cases majority of the attendances at ED are due to conditions that could be managed in primary care (Hendry 2005 and Gill 2013).

GP OOH services also experience high workloads in relation to the urgent care of CYP. For example, a contact rate with GPs in Buckinghamshire was 473/ 1000 population/year in the 0-9 year age group and demonstrated the largest contact rate across the age spectrum of patients (0-80 years) with more than a quarter of patients being identified as not needing same day contact (Brogan 1998). The capacity of primary care to manage the healthcare needs of CYP is a particular problem (Atlas of Variation, ChiMat 2012) without taking into account the continued increase in demand for the use of urgent care services.

Previous work around the use of urgent care services for CYP conducted by the RCPCH (RCPCH 2015) showed that parents and carers of children (younger than five years) with fever experience a median number of three contact points with NHS services for conditions that lasted on average about three days. Many of these children had conditions that were self-resolving, yet were referred for further advice or management in relation to their condition. The report also highlights difficulties that parents and carers with CYP have, namely that there are multiple points of entry to NHS services without clear definition of what those services can do to meet the needs of the CYP. In addition these services may not have been able to address the needs of CYP leading to referral to other services (Maguire 2011).

Studies have explored the difficulties that parents and carers experience in making the 'right choice of where to go' for urgent care. These difficulties include: being unaware of what local emergency or urgent services were available, which of the services were most appropriate in particular circumstances, the poor co-ordination between services, and a lack of integrated care for individuals (O'Cathain 2008).

Pathways of paediatric care must include the adequate clinical assessment and commencement of treatment according to the patient's clinical status. This is to separate those children with an emergency presentation requiring immediate medical attention from those who have less urgent presentations and who can be managed by other providers of urgent care. Recent reviews have shown that a significant proportion of child deaths were avoidable if the right pathway of care had been followed at point of contact with the NHS. The 'Why Children Die' report (RCPCH 2014) reinforces the importance of high-quality clinical assessment, showing there were cases of children who died as the severity of their illness was not recognised at an early stage. Had they been adequately assessed they would have received the appropriate treatment at a time that could have been lifesaving.

Pathways of care should fit with the patient's clinical status, provide guidance and information to parents, carers and CYP about the condition, give safety netting as to what to do, use recognised national guidance where available for optimal management and help to organise urgent and emergency care services according to clinical needs.

The role of NHS 111

NHS 111 launched nationally in 2013 (NHS England 2014). Its aim is to improve patients' access to services as well as to improve efficiencies in the urgent care system, and to form a directory of appropriate local services for callers, according to their needs (Knowles 2014). By improving access to urgent care, the goal of NHS 111 is to increase efficiency in directing people to the right urgent care service and to reduce unnecessary calls to 999 emergency ambulance services (Turner 2013).

NHS 111 deals with large numbers of enquiries; across all age groups, there were nearly one million telephone consultations in June 2015, that is, about 40,000 people per day contact the service for help and advice across England. Information about the patients' conditions is processed through the clinical algorithms by the health adviser to make recommendations. These recommendations vary from self-help to the health advisor sending an ambulance vehicle to manage the patient, and reflect the range of local services available. There is currently little known about how parents, carers and CYP use the system, and a lack of both qualitative and quantitative outcome data.

The predecessor to NHS 111 was NHS Direct. NHS Direct was established in March 1998 to help provide telephone advice and guidance to callers. One key aim of NHS Direct was to function as a directing service for patients in England to access the appropriate provider of the urgent care system that would meet their needs. Previous studies of NHS Direct callers showed that the under-fives were among the highest users (Cooper 2005) and the pre-school age group accounted for approximately a quarter of all calls to the NHS Direct service (Payne 2001). Children and young people are amongst the highest users of the service and although NHS 111 holds information on the telephone calls it receives, there is little information on the specific needs of CYP who present to that service (RCPCH 2014).

NHS 111 Learning and Development Programme - Phase One

Previous work conducted by the RCPCH and Imperial College NHS Healthcare Trust looked at a cohort of children under 5 years of age with fever whose parents or carers had contacted NHS 111 (RCPCH 2015). The majority of parents and carers with CYP who had called the service were signposted to self-care, and a minority of children were directed to emergency services, with most being signposted to urgent care services. Records of NHS 111 for children were linked to the local ED records in St Marys Hospital Imperial College Healthcare NHS Trust to see if the children had attended ED. This data linkage revealed that relatively few children were directed to this particular ED from NHS 111. The majority of those who did attend ED had conditions that largely could have been managed in primary care services. The study offered proof of concept for linking data between NHS 111 and hospital records, but it was limited in that it studied one particular ED and did not include records from primary care. The study did not consider the NHS 111 calls that were not followed by visits to ED, or to visits to other EDs beside the single one in the study.

The previous study provided the impetus to link NHS 111 data to other NHS services, including out-of-hours GP care. It also highlighted the importance of considering whether CYP were satisfied with their care as this might influence how parents, carers and CYP use urgent care services.

NHS 111 LDP - call

This NHS 111 LDP call was for studies on service improvements to address the diverse needs of service users and was also open to studies on how coding, informatics and other technological applications could be employed to provide better patient outcomes. The NHS 111 LDP remit provided a framework for the project team to investigate the pathways and experience of care specific to parents and carers of CYP presenting to NHS 111 with common conditions.

NHS 111 LDP - remit

The overarching remit of the NHS 111 LDP was to evaluate the following key areas:

- Service improvements that provide more personalised services to support the diverse needs of people using the NHS 111 service
- Delivery of technical and informatics enhancements to the NHS 111 service, in particular those that improve integration across the health service.

The RCPCH and collaborators (The Health Foundation, the Picker Institute Europe, with paediatricians from Imperial College NHS Healthcare Trust, and University College London) were

one of the 35 successful teams in their application to the programme. The main focus of the RCPCH-led collaborative project was to study the experience and patient flow of CYP presenting to NHS 111 with one of four common conditions.

The RCPCH and collaborators proposed the following objectives:

- To investigate the feasibility of linking NHS 111 data with wider NHS administrative data to understand the predictors of healthcare utilisation, following advice from NHS 111
- To understand how parents and carers use NHS 111, their experience of the call and their actions as a result of calling
- To identify how parents and carers feedback can be used to improve the service provided in the future.

Overview of project work packages

The project objectives outlined above were achieved through three discrete yet complementary work packages. The three work packages aimed to identify patient flow through data linkage, assess patient experience through the development of a PREM, and to understand what parents, carers and CYP value in a telephone advice service such as NHS 111.

Parts 1-3 of this report present each of the work packages. They are structured in two sections, with the first describing the approach taken and the second describing the emerging results.

The three work packages focus on CYP under 16 years with one of four common conditions namely; fever, diarrhoea and vomiting, breathlessness and constipation. The reasons for choosing these four conditions are as follows: the first three conditions are amongst the most common childhood presentations to urgent care services (Armon 2001, and Sands 2012), whilst constipation is a common chronic condition managed in the primary care setting and does not tend to present acutely with potentially life threatening complications as can occur with the first three presentations. All four are associated with recognised national guidance through the National Institute for Health and Care Excellence (Appendix 1 – NICE guidelines). Breathlessness in childhood may refer to a number of different diagnoses including acute bronchiolitis and asthma. These pathways of care are also recognised by the RCPCH Asthma Care Pathways (RCPCH, 2011) (Appendix 1 – RCPCH care pathways). The conditions provide measurable markers of care that should be delivered to CYP according to their clinical condition, from their initial assessment to the suggested treatment regime according to their medical status. These common childhood conditions also provide a foundation for future work.

Part 1: Data linkage

Aims

Part 1 of the project aimed to:

- Establish the **feasibility of linking** person-level data from NHS 111 to data on healthcare utilisation following telephone calls to NHS 111 in North West London
- By establishing the feasibility of linking person-level data following the NHS 111 call, the project team were equipped with the tools to **implement** an analysis of the linked data.

This analysis focussed on assessing service use following NHS 111 telephone calls and examining which patient factors were associated with attending ED following the NHS 111 calls.

This section outlines the feasibility of collecting and linking the data, and sets out some observations about the completeness of NHS 111 data. The next section presents the preliminary findings.

Feasibility of data linkage

The Health Foundation (THF) worked closely with the North East London Commissioning Support Unit (NEL CSU) to develop the process for linking NHS 111 with GP OOH and SUS data.

Methods

Information governance framework

Given the retrospective nature of the analyses and the large number of patients involved, it was essential to put in place strict controls to protect the identities of the patients represented in the data. This piece of work was conducted under the terms of service improvement conditions, and included approval by the involved Caldicott Guardians.

Data protection

The analytics team worked closely with NEL CSU to agree an approach to 'pseudonymising' the data before it was transferred to the analytics team. NEL CSU removed data fields that could directly identify patients, including their name, address, and date of birth. However, the age of the patient was included in the data set to allow quality checking. A unique patient reference number derived by NEL CSU was added to the data set so that the analytics team could identify records belonging to the same person, for example, people who had made successive calls to NHS 111, or a call to NHS 111 followed by an ED visit. NEL CSU also included variables for small area of residence (Lower Super Output Areas, each corresponding to around 1,500 individuals across all ages). Without the aforementioned steps taken by NEL CSU to retrieve the relevant data for this study, the analysis could not have been conducted.

Even pseudonymised data carry a residual disclosure risk, since it is theoretically possible that, by combining these data with other information, one could identify individuals within the data set. Therefore, the data for this project were stored and processed within an accredited, secure environment at The Health Foundation. This secure environment was designed using the ‘five safes’ framework, which recognises that, in addition to pseudonymising data, there are many other types of controls that need to be put in place to protect patients’ identities. These other controls are outlined in Box A:

Box A: Important controls regarding data protection for routinely collected data

- **Safe settings:** For example, data were held only in encrypted form, and access to the processing servers was provided through thin clients, whereby all communication between the client and the secure environment was encrypted.
- **Safe people:** For example, all members of staff with access to data were trained in information security, data protection legislation and statistical disclosure control. They are also contractually held to non-disclosure agreements.
- **Safe projects:** For example, access to data was controlled at the project level, so that only individuals working on the project could view it.
- **Safe outputs:** For example, research outputs (e.g. regression coefficients) were manually checked before release for publication to ensure that research findings were non-disclosive.

Data extraction

Before extraction of any data, THF obtained permission from the governance lead of the NHS 111 LDP to hold and process the NHS 111 data and GP OOH data for North West London. The Caldicott Guardian for NHS West and Central London subsequently provided permission to link hospital data from SUS to the NHS 111 data. The relationship between THF and the Caldicott Guardian was facilitated by the Head of Strategic Planning at NHS West London Clinical Commissioning Group (CCG).

The SUS data were transferred from the South London Commissioning Support Unit to NEL CSU. NEL CSU, who already held NHS 111 and GP OOH data, facilitated the linkage and pseudonymisation of the data. All data were then transferred to THF for processing.

Results

Data linkage challenges

Even with the support of NEL CSU, amassing the data for this project was not without challenges, many of which are common to data linkage studies of this type. First, although it was hoped to obtain data from general practices for this study, these data could not be obtained as the GP data for North West London were not stored centrally. The inclusion of GP data could be explored in future work. It was, however, possible to obtain data on appointments with out-of-hours general practice care.

Another challenge concerned navigating the system for accessing healthcare data. It was unclear which organisations were the data controllers for each of the data sets considered for this study, and the process for obtaining permission to access data varied between the data sets concerned. Some of these challenges seem to have been exacerbated by the closure of the North West London Commissioning Support Unit just before the start of the work, in November 2014.

Data sets and data completeness

Data were obtained for 39,177 telephone calls made to NHS 111 between April 2013 and February 2015. These calls were for children under 16 years of age (i.e. 15 years and 364 days or younger) who were living in the Hammersmith and Fulham, Central London and West London CCG areas. Data on 96,879 out-of-hours general practice appointments and 74,443 Accident & Emergency attendances were also received. The out-of-hours GP data was limited to providers in the three CCGs, while the secondary care data reflected all recorded NHS funded care in England for patients resident in the three CCGs.

The ED, outpatient and inpatient data were sourced from SUS, which is effectively a local version of the widely used Hospital Episode Statistics. Its strengths and limitations for research and service evaluation purposes have been relatively well documented (Spencer & Davies 2012). The use of person-level data from GP out-of-hours and NHS 111 services was much more novel. An important output of this study is therefore an analysis of the characteristics of these data, since these were largely unknown at the outset of this feasibility study.

NHS 111 data limitations and results

The NHS 111 data used had some significant limitations:

- *Data completeness:* One of the disposition codes used in the NHS 111 data refers to the patient being 'unwell and less than 1 year old'. This code was used in 47% of all calls related to children under one year of age. While the primary purpose of a code set is operational rather than for research, use of this code limited our ability to identify children under one year old with the four particular conditions that were of interest. For example, no children under one year old were recorded as having fever.
- *Ambulance call outs:* Data completeness was much lower for calls that were transferred to the emergency services than for those that were not transferred. For example, there was very little information on the symptoms of patients routed to the emergency services, even though this field was populated for 85% of calls that were not thus routed. This meant that we could not examine critical issues regarding transfer between these services.
- *Missing records:* Some unusual patterns within the data were identified. For example, the volume of NHS 111 calls in North West London increased sharply in September 2014, from between 944 and 1,787 calls per month before this date, to between 1,815 and 3,332 calls per month afterwards. A plausible explanation is that some of the earlier calls were missing from the data, perhaps due to changes to the information management systems.
- *Type of information recorded:* GP OOHs appointments were often recorded as happening within minutes of the end of a NHS 111 call. A likely explanation is that patients were immediately patched through to the GP OOH service, either to speak to a member of the out-of-hours team or to make an appointment for a later point in time. This meant there was some uncertainty

about when patients spoke with the out-of-hours team and, indeed, whether they attended the appointments that had been made for them.

- *Accuracy*: In this project, we did not set out to confirm the accuracy of the data. In particular, we could not confirm the recorded symptoms or the accuracy of the records about the recommendations that were made to patients.

The data analysed in this study were originally collected for the purposes of delivering healthcare rather than for service evaluation or research. There may be good reasons for the data collection protocols that were followed, including the need to route some calls rapidly to the emergency services. However, if the NHS is to use similar data to improve the quality and safety of healthcare, then at a minimum these features of the data will need to be better understood (Deeny & Steventon 2015). Qualitative research into how the information management systems are used in practice may be warranted.

Implementation of data linkage

Having shown the feasibility of obtaining and linking this data, this section presents the provisional findings from the analysis of linked data. This includes the characteristics of NHS 111 calls and factors associated with attending ED following a NHS 111 call.

Results

Some of these analyses focussed on the entire set of calls made for children under 16 years of age (n=39,177), while others address calls for the four particular conditions (n=1,405 for breathlessness; 3,036 for diarrhoea or vomiting; 196 for constipation; and 1,483 for fever). The analysis for fever was restricted to children aged under 6 years rather than under 16 years as for the other parts of this report.

NHS 111 call volumes were heavily skewed towards younger ages

Call volumes were highly skewed towards younger ages. For example, within the overall cohort, 10,140 calls were made for children under one year of age, compared with 3,544 calls for children aged three (Figure 1). A similar, but less marked, pattern was observed within each of the four condition groups (Table 1). The reason for the less marked age gradient within the four symptom groups might be related to the use of the 'unwell and less than 1 year old' code that was discussed previously. By focussing the analyses on calls that had certain symptoms recorded, we under-represented younger children whose symptom was either not elicited or not recorded.

Figure 1: Number of NHS 111 calls by the age of the patient

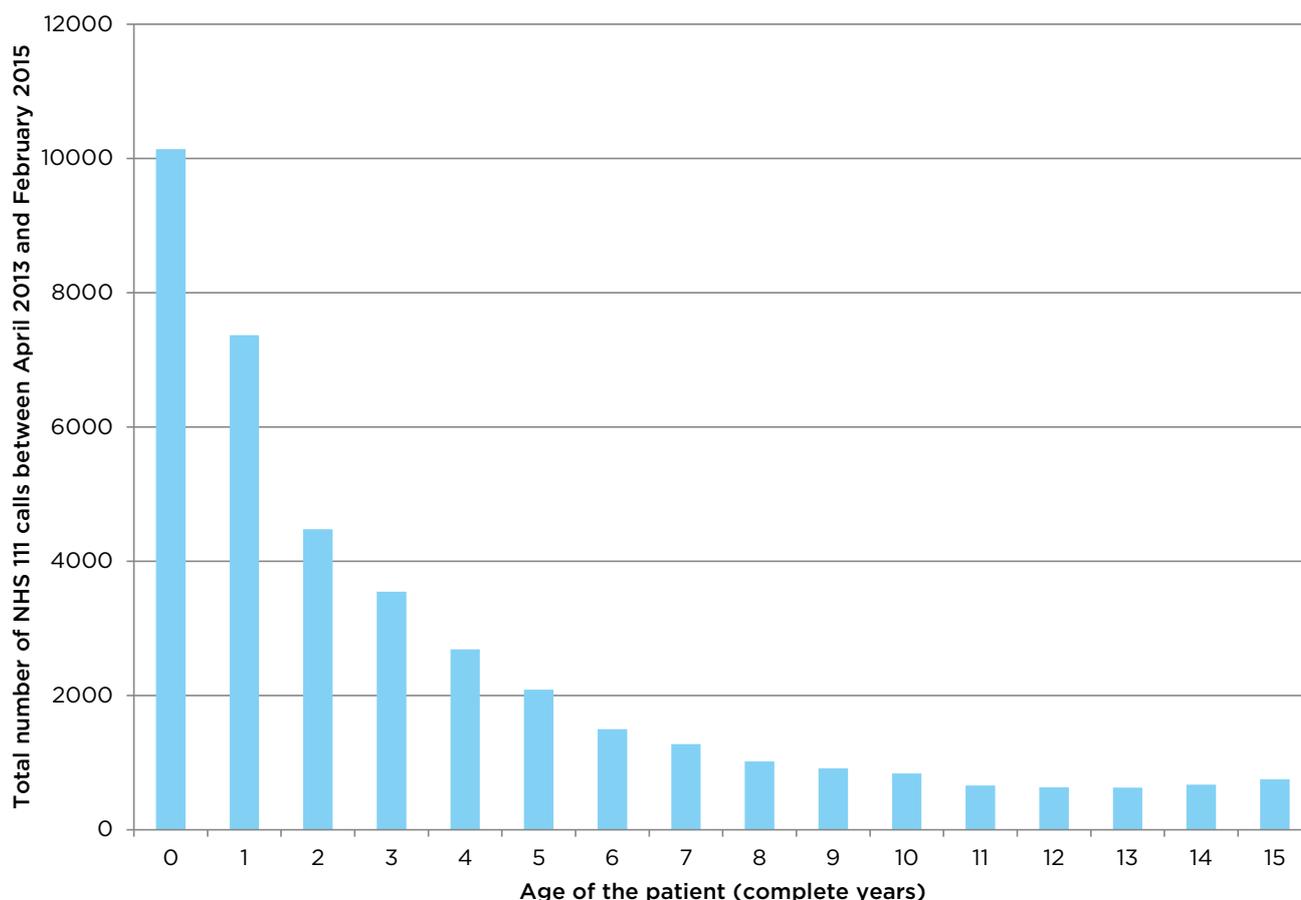


Table 1: Number of calls to NHS 111 by age in years (% across condition)

	Breathlessness (n=1,405)	Constipation (n=196)	Diarrhoea and vomiting (n=3,036)	Fever (n=1,483)
Under 1	18 (1%)	55 (28%)	137 (5%)	0
1-3	1021 (73%)	89 (45%)	1687 (56%)	1286 (87%)
4-5	196 (14%)	19 (10%)	450 (15%)	197 (13%)
6-10	119 (8%)	25 (13%)	529 (17%)	-
11-15	51 (4%)	8 (4%)	233 (8%)	-

Note: This table shows ages in bands for data protection reasons. Our analysis for fever was restricted to children aged under 6 years. There were no records of fever for children aged under 1 year. These age bands were generated for theoretical and data protection reasons. It was assumed that fever may be more prevalent in younger children, for example under 1 year old, and that younger children may exhibit different health needs and use of NHS 111. No children under 1 year old were recorded as experiencing fever. These children may have been recorded as 'unwell and less than 1 year old', or they might have been routed immediately to the emergency services.

NHS 111 call volumes were considerably higher outside of normal office hours

As might be expected given the nature of NHS 111, call volumes were highest outside of normal office hours. For each of the four conditions, there was at least a 1.5-fold increase in daily call volume on Saturdays and Sundays compared with during weekdays. For example, across the study period, an average of 152 calls were made each week day for children experiencing breathlessness, compared with 322 calls each day during the week. Call volumes varied during the course of the

week day, reaching their highest levels in the evenings, but with a smaller peak at around 8 to 9am (Figure 2). This pattern did not exist during the weekend (Figure 3).

Figure 2: Total number of NHS 111 calls made per hour during weekdays (across the conditions and age groups studied)

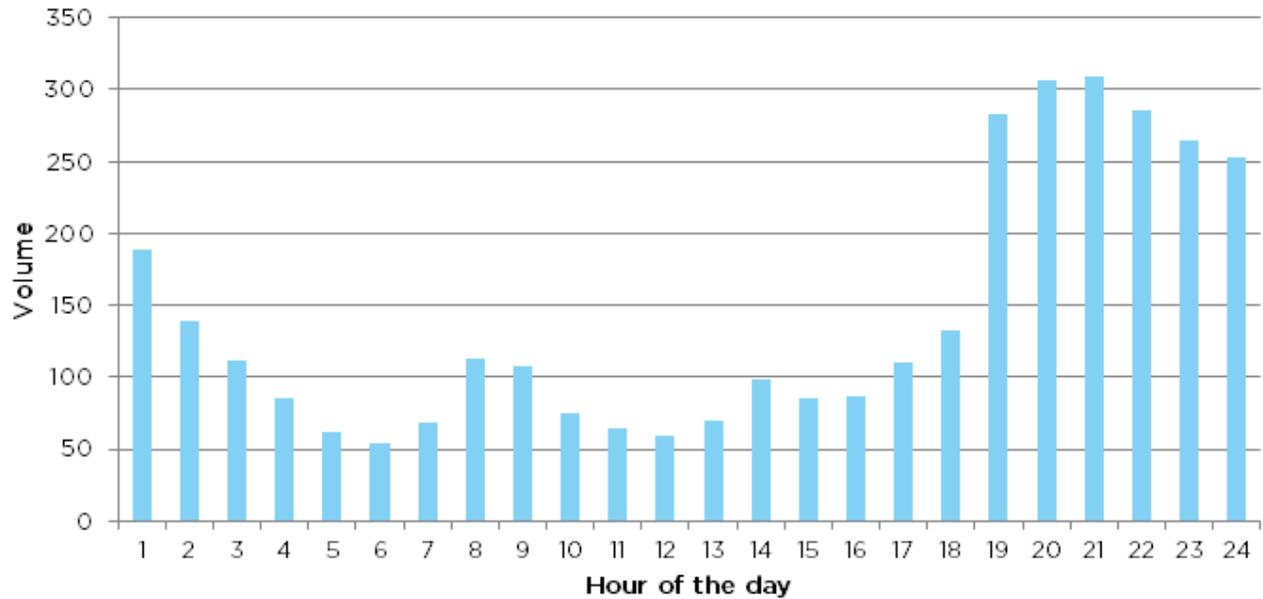
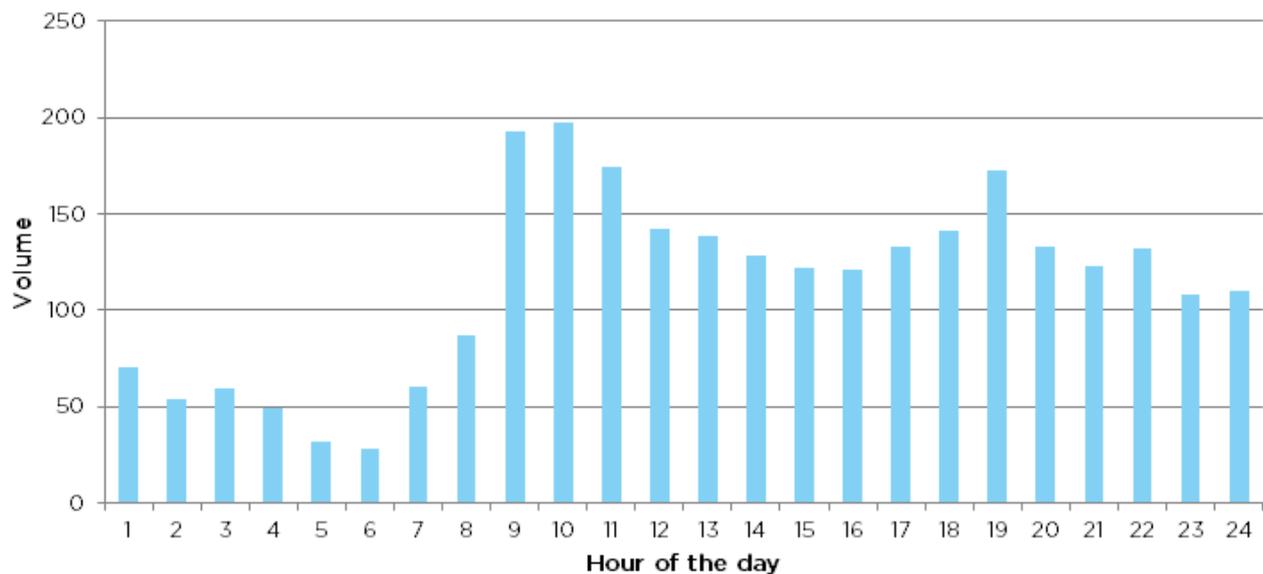


Figure 3: Total number of NHS 111 calls made per hour during the weekend (across the conditions and age groups studied)



The data were consistent with the NHS 111 call being the first point in the care pathway

NHS 111 calls were only rarely preceded by a visit to ED or out-of-hours GPs. For example, only 3% of the people calling with breathlessness had attended an ED within the previous week, and only 2% had made an appointment to see an out-of-hours GP during the same timeframe (Table 2). Indeed, some of the previous contacts may have related to symptoms other than breathlessness. Table 2 shows similar patterns for the other conditions.

Table 2: Prior healthcare utilisation for children who were the subjects of calls to NHS 111 (numbers of patients and % across condition)

	Breathlessness (n=1,405)	Constipation (n=196)	Diarrhoea and vomiting (n=3,036)	Fever (n=1,483)
Out-of-hours GP appointments prior to the NHS 111 call				
Previous 24 hours	13 (0.1%)	*	21 (0.7%)	28 (2%)
Previous 7 days	30 (2%)	*	84 (3%)	47 (3%)
Previous 30 days	54 (4%)	*	113 (4%)	70 (5%)
ED visits prior to the NHS 111 call				
Previous 24 hours	13 (1%)	*	51 (2%)	32 (2%)
Previous 7 days	48 (3%)	10 (5%)	126 (4%)	64 (4%)
Previous 30 days	82 (6%)	18 (9%)	201 (7%)	106 (7%)

Note: Small numbers have been suppressed (*) for data protection reasons. The analysis for fever was restricted to children aged less than 6 years.

Patients were almost always advised to follow up with their GP rather than ED

The NHS 111 data set records the ‘disposition’ of the call – whether or not the patient was recommended to follow up with another healthcare provider, and if so the type of provider that was recommended. According to these data, the vast majority of patients were advised to visit their GP or other local service (77%, see Table 3). In addition, 19% of patients were advised to speak to (but not visit) their GP. Very few patients were advised to go straight to the ED (n=66/6120).

A significant proportion of NHS 111 callers subsequently attended ED

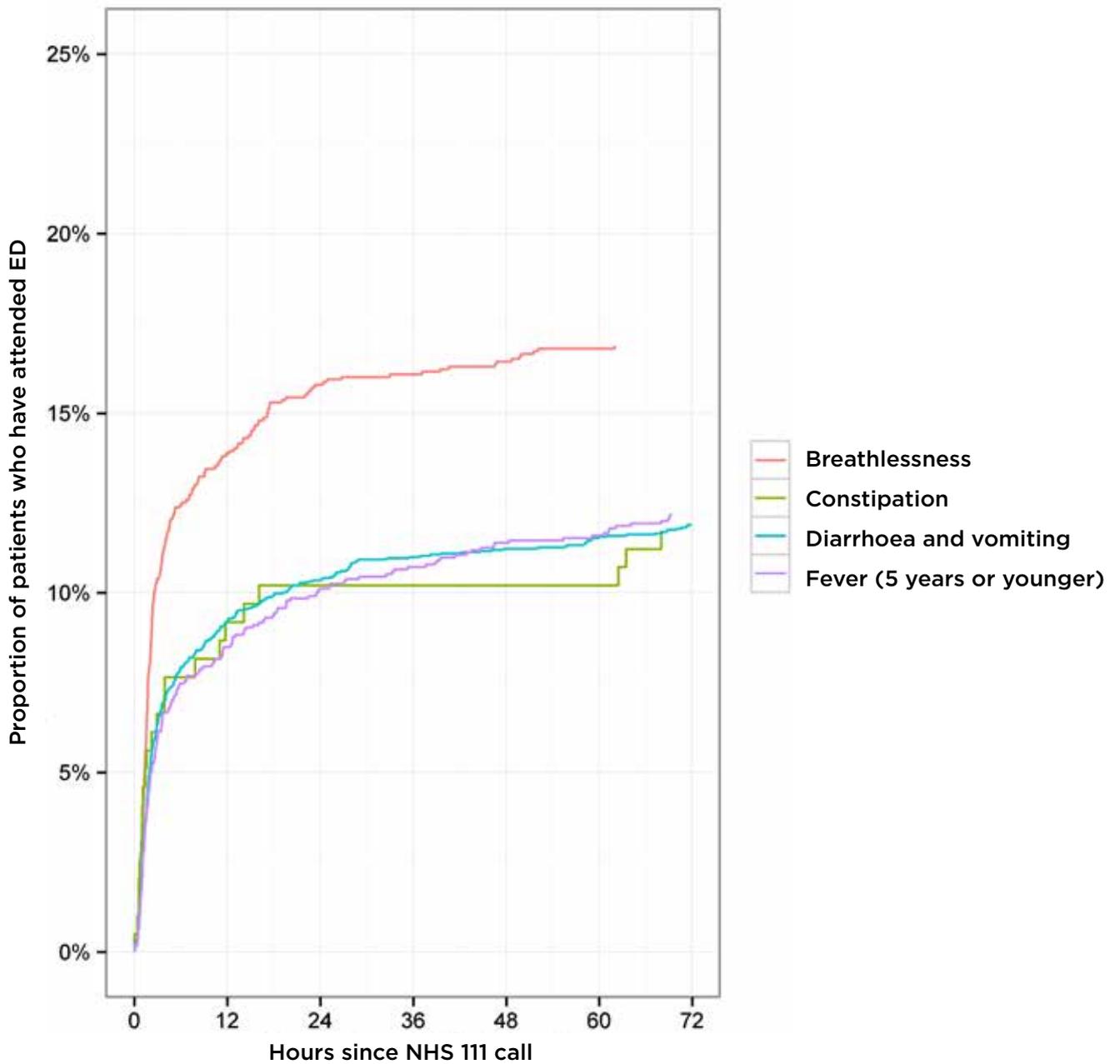
Although only 1.1% of people calling NHS 111 with breathlessness, constipation, diarrhoea and vomiting, or fever were advised to go to ED, 440 patients visited ED within three hours of the call. Over 95% of the patients attending ED had been advised by NHS 111 to follow up with their GP. Children complaining of breathlessness were more likely to attend ED than the children presenting with the three other symptoms (Figure 4).

Table 3: Advice given to NHS 111 callers about where to seek further care (numbers of patients and % across condition)

	Breathlessness (n=1,405)	Constipation (n=196)	Diarrhoea and vomiting (n=3,036)	Fever (n=1,483)	Total (n=6,120)
Attend ED department	34 (2%)	0 (0%)	32 (1%)	0 (0%)	66 (1%)
Visit GP or local service	864 (61%)	123 (63%)	2430 (80%)	1,291 (87%)	4,708 (77%)
Within 2 hour	65 (5%)	21 (11%)	1,080 (36%)	923 (62%)	2,089 (34%)
Within 6 hour	799 (57%)	49 (25%)	617 (20%)	246 (17%)	1,711 (28%)
Within 24 hours	0	53 (27%)	733 (24%)	122 (8%)	908 (15%)
Speak to GP practice	502 (36%)	52 (27%)	434 (14%)	191 (13%)	1,179 (19%)
Other	5 (0%)	21 (11%)	140 (5%)	1 (0%)	167 (3%)

Note: Our analysis for fever was restricted to children aged under 6 years. The ‘other’ category includes advice to contact GP if symptoms recur/persist and home management.

Figure 4: ED attendance of children following NHS 111 calls for the four conditions



A multivariable analysis across all four symptoms (n=6,120) was used to test whether certain patient characteristics were significantly associated with ED attendance within three hours following the call to NHS 111. For the preliminary analysis presented in this report, the range of patient characteristics was limited to age, symptom and whether the call was made at the weekend or during the week. The analysis was conducted using Cox regression (Cox & Oakes 1984) and confirmed that, after adjusting for the other variables, patients with breathlessness were significantly more likely to attend ED than patients with the other conditions (hazard ratio for breathlessness versus fever: 1.74, 95% CI, 1.33-2.27, $p < 0.01$). Although the associations were not statistically significant, we did find that older age was associated with increased ED attendance (hazard ratio for each additional year of age: 1.02 95% CI, 0.99-1.05, $p = 0.22$). Calls made at the weekend were less likely to be followed by an ED visit than calls made during the week (hazard ratio 0.92, 95% CI, 0.76-1.11, $p = 0.38$) but, again, this association was not statistically significant at the 5% level, so it may have been a chance finding.

Part 1: Conclusions

This study has established the feasibility of linking data on NHS 111 calls to data from out-of-hours general practices and secondary care at the person level for large numbers of people aged under 16 years with four common conditions. ED attendance was relatively rare following NHS 111 calls, with only 7% of patients attending ED within 3 hours of the call. However, over 95% of those patients going to ED had been advised by NHS 111 to follow up with their GP.

This study suggests that linked data sets could be used to identify opportunities to improve the quality and efficiency of healthcare. ED visits may not always best suit the patients' needs and they are often costly to the NHS. Analysis of linked data might help identify groups of callers at particularly high risk of attending EDs. However, it could not be determined how many of the ED visits were appropriate, or indeed whether a healthcare professional who was not part of the NHS 111 team (e.g. an out-of-hours GP) referred the patient to ED at some point after the NHS 111 call. Future work to address these limitations is warranted, as well as to examine calls for other symptoms than those examined in this report.

While routine data offer a population-level view of the patterns of healthcare utilisation, they provide a limited amount of information about the experience of individual patients. It is important to know the users experience of the service as this may influence their decision as to what pathway of care they choose to follow. This area is explored in Part 2 of this report.

Part 2: Patient Reported Experience Measure (PREM) for NHS 111

Aims

Part 2 of the project aimed to:

- Establish the **feasibility of developing a PREM** specific to parents and carers of children under 16 years, who have called NHS 111 on behalf of their child or young person for one of four common conditions.

By understanding the **feasibility of developing a PREM** specific to the NHS 111 service, the project team were equipped with the tools to develop and **implement** the survey.

Implementation of the PREM aimed to:

- Investigate parents and carers perceptions of NHS 111; particularly their experience of using the service on behalf of their child, to understand when parents and carers opt to use NHS 111, what is important when using the service, what factors may influence their decision to follow advice and to explore whether the most appropriate care pathway is followed.

Feasibility of PREM development

The Picker Institute led on the development and implementation of a PREM specific to parents and carers of CYP that had used the NHS 111 service.

Methods

Stage 1: Focus group methods

A total of four focus groups were held, one specifically for each condition (fever, breathlessness, constipation, and vomiting and diarrhoea), each with between four and nine participants who had recently called NHS 111 about the care of their child. Representatives at the focus groups were recruited via an external recruiter using a panel database as well as targeted social media such as mumsnet.com.

Participants were screened using pre-determined criteria including date of their last call to NHS 111, the reason for calling, and age of child about whom they called NHS 111. Recruitment oversampled to compensate for no-shows at the focus groups, with the aim of ensuring that at least four and ideally eight parents or carers attended each of the focus groups. The focus groups were facilitated by Picker Institute Europe staff in central London in February 2015. Focus groups followed an open semi-structured discussion to understand parents and carers recent experiences of calling NHS 111 for their child, why they used NHS 111, what worked well and what could have been improved. Table 4 shows the characteristics of focus group participants for each condition.

Table 4. Breakdown of focus group participants according to fever, breathlessness, diarrhoea and vomiting or constipation

		Group 1: Fever	Group 2: Breathlessness	Group 3: Vomiting and Diarrhoea	Group 4: Constipation
Number of participants (n)		9	9	9	4
Parent caller (n)	Mother of child	7	9	9	3
	Father of child	2	0	0	1
Age of child in years (n)	0 - 1	1	4	0	1
	2 - 3	5	1	1	2
	4 - 5	0	3	3	0
	6 - 7	1	0	2	1
	8 - 11	1	1	1	0
	12 - 15	1	0	2	0

Stage 2: Focus group results to inform questionnaire

The focus groups revealed that many parents and carers use NHS 111 when other services are not available or feasible; it was not necessarily their first choice of service. Having confidence and feeling reassured by the NHS 111 operator seemed to be key in determining whether parents and carers followed the advice they received during these telephone calls. Those who felt they were listened to and received clear information from NHS 111, also reported following the advice they received. In contrast, those who felt they were not listened to, or did not trust the advice they received as being appropriate, went on to seek assistance elsewhere, for example at a local ED. This pattern was similar for all four conditions.

Stage 3: Cognitive interview methods following focus groups

Findings from the focus groups, in addition to existing Picker Institute PREM questions, informed the first draft of the questionnaire. The first draft was consulted on by stakeholders including healthcare professionals and NHS 111 representatives. The draft version was then tested by employing telephone cognitive interviews with 27 parents and carers who had recently used the service over three rounds, with amendments being made between each round according to the feedback obtained. Each cognitive interview lasted approximately 35-45 minutes, and tested the survey questions for comprehension and to ensure that they were interpreted as intended, as well as testing the choice of response options, recall, the instructions (including routing between the questions), and the overall suitability of the questionnaire. The tool was updated after each round of interviews according to findings from previous interviews. It was then cognitively retested until the researchers were satisfied that the final questionnaire was fit-for-purpose, i.e. was relevant to the target population and that there were no further issues arising.

Participants in the cognitive testing were recruited via an external recruiter using similar methods to the focus groups i.e. a panel database as well as targeted social media inviting. Those who showed an interest were screened using pre-determined criteria including the last time they called

NHS 111 on behalf of their child (which had to be within the last 6 months), the age of the child they called NHS 111 for, and the condition about which they called the service. Recruitment ensured that a roughly even spread across the four conditions was achieved. Table 5 presents the breakdown of participants for all three rounds of cognitive interviews.

Table 5. Breakdown of cognitive interview participants according to condition, age of child at the time of call and the parent who called NHS 111

Cognitive testing interviews participants	Number
Condition	
Fever	6
Breathlessness	8
Vomiting & Diarrhoea	7
Constipation	6
Age of child at time of call (yrs)	
0 - 1	9
2 - 3	7
4 - 5	5
6 - 7	1
8 - 11	3
12 - 15 years	2
Parent who called NHS 111	
Father	4
Mother	23

Stage 4: Cognitive interview top line results

The cognitive interviews highlighted a few problems with the draft questionnaires, including issues with instructions, question wording and response options. For example, participants were unclear whether they could select more than one response option for question 1 'How did you learn about NHS 111'. This question was revised to direct parents and carers to think about where they **first** learned about NHS 111: 'How did you **first** learn about NHS 111? **Please tick one only**'.

Some questions were also removed completely from the survey based on the findings from the cognitive interviews. For example, the original draft questionnaire included the question:

'What was the **most important** thing you wanted from the call? **Please tick one**'.

1. To be assisted quickly
2. For the operator to listen to me
3. To receive advice
4. To be reassured
5. To receive empathy and care
6. To get a referral to another health service
7. Other (please specify)

A number of parents were unable to choose only one reason, in fact almost all participants noted that as a concerned parent, all the response options were important and they wanted to select all response options. It was decided the question would not provide any meaningful results, so it was removed.

Similarly, the following two questions were removed as parents found it difficult to distinguish between them. Further, parents interpreted the word “reassured” quite differently in Q8. Some interpreted as: the first person they spoke to reassured them that what they were doing to assist their child was correct; and others feeling that they were reassured that the first person they spoke to knew what they were doing.

Q6. Was the advisor caring and sympathetic?

Q8. Did you feel reassured by the person you spoke to?

The other factors that influenced the production of the final PREM were also documented, and a summary report containing all changes made to the survey after each round of cognitive interviews is available upon request from the Picker Institute, subject to permission from the RCPCH.

Stage 5: Consensus involved in forming the final PREM

Although it was originally planned to develop four separate PREM, i.e. one for each condition, findings from the focus groups, supported by cognitive testing, showed no difference in the relevance of the questions. The project team therefore agreed that one PREM was to be piloted for all four conditions (i.e. the four surveys should present the same questions).

Stage 6: Contents of the final questionnaire

The final questionnaire is four pages long and asks parents or carers about a most recent call to the NHS 111 service. It was designed to obtain information on the pathway of care through NHS 111. It captures: the reasons why the parents or carers used this service as opposed to another healthcare service, their experience of the NHS 111 call itself, including their perceptions of the operators and healthcare professionals to whom they spoke, the advice received, the actions taken, and finally where their care pathway ended, for example at secondary care.

Implementation of the PREM

Following the development of the PREM the Picker Institute implemented the PREM in North West London using a telephone methodology.

Methods

The Picker Institute developed a data specification request containing details of records of all parents or carers who called North West London NHS 111 between March and June 2015 on behalf of their child under 16 years (i.e. up to 15 years and 364 days) for one of the four conditions. The sample request included¹:

¹ Details were required for the demographic batch trace to ensure no children who may have passed away were included in the sample.

-
- Call date and time
 - Caller name
 - Caller relationship
 - Caller phone number
 - Address of parent who called
 - Condition called for
 - Age of child/patient
 - Forename of child/patient
 - Surname of child/patient
 - DOB of child/patient
 - Gender of child/patient

The Picker Institute employed a telephone survey methodology as this is the mode by which parents or carers contacted NHS 111 meaning that their telephone details would be most up-to-date. This method was believed to be the most effective way of getting the best response as opposed to other methods such as by sending questionnaires by post. This is the method most likely to be used in future studies owing to its relative efficacy in securing representative sampling.

Information governance framework

The Picker Institute maintain certifications to ISO 20252 and ISO 27001, which guarantees that all information is handled securely and comply with the Data Protection Act 1998 and the Market Research Society's (MRS) Code of Conduct. Further, all patient identifiable data is only transferred to the Picker Institute via their secure file transfer (FTP) site and used solely for the purpose of carrying out the survey fieldwork. The formal data request along with the Picker Quality Assurance and Information Security policy were approved by the NHS 111 LDP governance lead under the governance permissions of the NHS 111 Phase 2 Learning & Development Programme (details available on request).

The sample data underwent a Demographic Batch Trace to remove the patient details of children who may have died, so no telephone calls were made to parents or carers of these individuals. NEL CSU devised an IG-compliant submission pipeline for the purposes of providing the Picker Institute with all the components of the Data Request. This pipeline directed the records containing the data covering the above bullet points, derived from the low-level telephony data straight from the Provider's secure environment to the Picker Institute's secure FTP. In addition, sufficient fields for the DBS trace were obtained from the Provider into the NEL CSU DSCRO environment; and the DBS output (deceased/not deceased) were transferred to the Picker Institute via FTP, together with indices allowing the full data set to be assembled in a secure environment.

Results

Survey activity

A sample of 4415 parents and carers who called NHS 111 in NWL between March and June 2015 on behalf of their child (under 16 years) for one of the four specified conditions was drawn. The telephone survey interviews were conducted from 6 August to 2 September 2015 using a staggered approach, targeting those who had called NHS 111 for constipation in the first instance to ensure

similar number of responses across the four conditions was achieved. This was necessary given the lower number of parents or carers calling for constipation in the submitted sample. The target of 1000 completed surveys was achieved within the fieldwork period. Full breakdowns of the call status at the end of the study are presented in Table 6 below.

Table 6. Call status at end of data collection period by each of the four conditions

	Fever (n)	Diarrhoea and Vomiting (n)	Breathlessness (n)	Constipation (n)
Completed survey	305	264	331	100
Callers who answered the survey call	428	338	458	30
Appointment scheduled to complete survey	58	88	96	16
Refusal to complete questionnaire	86	63	128	34
Unavailable during study period	82	48	89	22
Busy/Call rejected/ No reply	449	493	286	29
Stopped/Terminated the conversation	10	6	5	2
Wrong number	12	14	28	2
Language barrier	1	9	3	2
Total	1431	1323	1424	237

Table 7. Presents the number of people sampled for each of the four conditions, along with the response rate for each condition

Condition	Number called (n)	Number completed (n)	Response rate
Fever	1431	305	21%
Breathlessness	1424	331	23%
Diarrhoea and Vomiting	1323	264	20%
Constipation	237	100	42%

Note: Percentages have been rounded to the nearest whole number here and throughout this section

Table 8. Overview of demographic characteristics of respondents according to age, gender, ethnicity and the main person that completed the questionnaire

Respondent Characteristic (n=1000)	Number	Percentage
Age of child at time of call (yrs)		
0 - 1	510	51%
2 - 3	264	26%
4 - 5	102	10%
6 - 7	54	5%
8 - 11	47	5%
12 - 15	23	2%
Child gender		
Male	558	56%
Female	435	44%
Child ethnicity		
White British	341	35%
White other	131	13%
Mixed or multiple ethnic group	206	21%
Asian or Asian British	150	15%
Black or Black British	133	14%
Other	25	3%
Main person who completed questionnaire		
Mother of child	773	77%
Father of child	203	20%
Mother and father together	5	1%
Carer/guardian of child	2	<1%
Other	17	2%

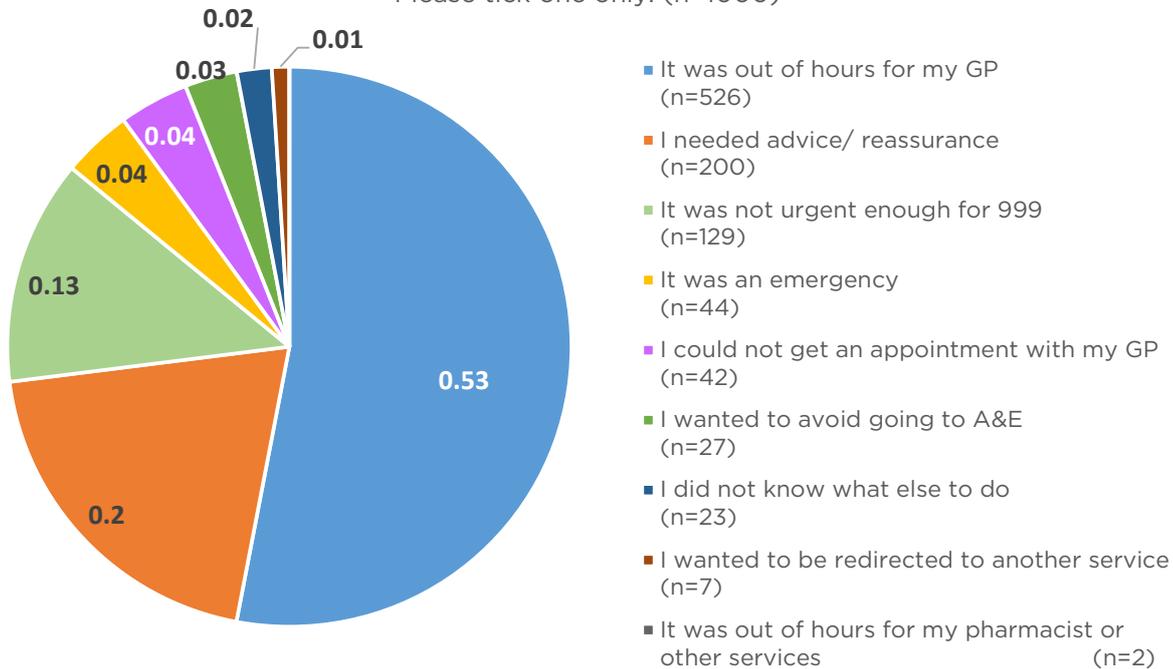
Top line results

For all the four conditions, the most common reason parents or carers reported calling NHS 111 rather than using another service was that it was out-of-hours for their GP (53%, n=526). Twenty percent (n=200) stated that they called for advice or reassurance, and 13% (n=129) stated the main reason for calling NHS 111 was because their child's illness was not urgent enough to ring 999.

These findings mirror those from the focus groups where parents and carers had reported that NHS 111 was not necessarily their first choice. The focus groups also said that they called NHS 111 for reassurance and advice. Graph 1 below shows breakdowns for all response options.

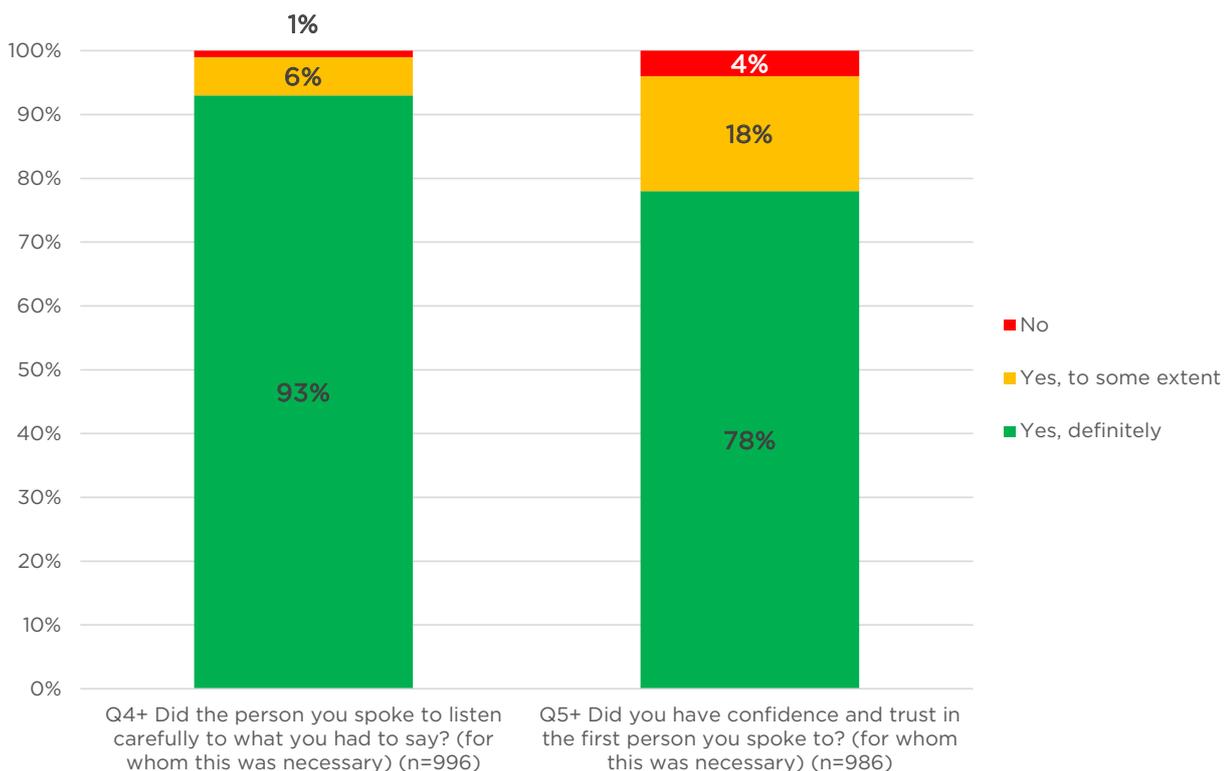
Graph 1. The main reason parents or carers called NHS 111 rather than another service

Graph 1. Q2. Thinking about the most recent time you called NHS 111, what was the **main reason** you called NHS 111 rather than using another service? Please tick one only. (n=1000)

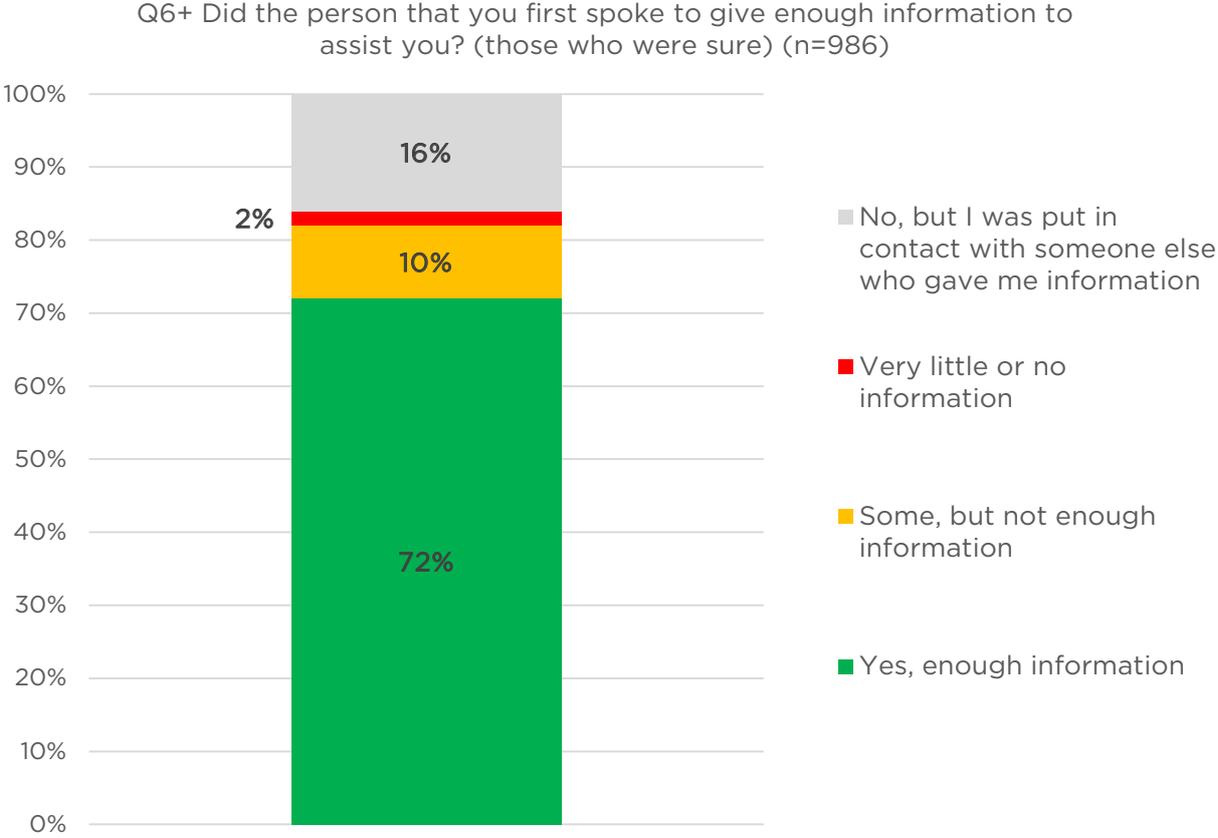


Most parents or carers were positive about the first person they spoke to at NHS 111, with 99% (n=731) of responders who could remember stating that the operator introduced themselves and 93% (n=923) reporting that they felt the operator listened to them carefully (in the group who responded that this was necessary). Further, over three quarters of respondents had confidence and trust in the first person they spoke to (78%; n=772), and over two thirds of respondents were given enough information to assist them (72%; n=709).

Graph 2. Parents or carers experience of the call about their interaction with the health advisor



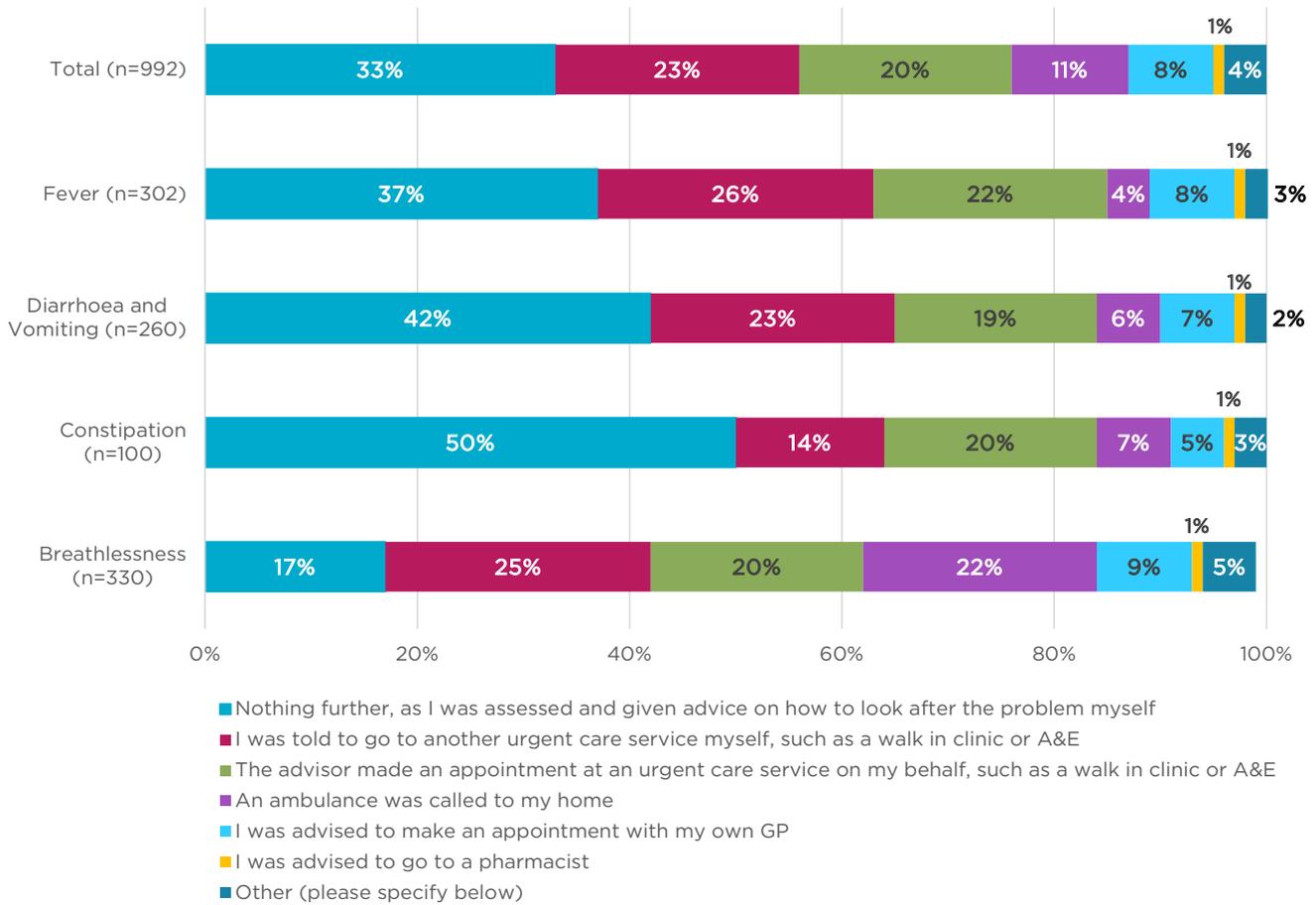
Graph 3. Parents and carers perceptions of whether they received enough information to assist them



Overall, the most common outcome reported by one third of parents and carers was that they were assessed and given advice on how to look after the problem themselves (33%, n=328). A further 23% (n=232) were told to go to another urgent care service such as walk-in clinic, and for 20% (n=202), an appointment at an urgent care service was made for them by the advisor. (Appendix 2, Frequency tables Q9).

As specified by the NICE guidelines and supported by findings from the focus groups, for those parents or carers calling for their child’s breathing problem, the most common advice or action received was to attend another urgent care service (25%; n=81). NHS 111 called an ambulance directly to the home for 23% of respondents who had called for breathlessness (23%, n=74). Those who called regarding the other three conditions all reported the most common outcome to be receiving advice on how to look after the problem themselves. Graph 4 below provides breakdowns by condition.

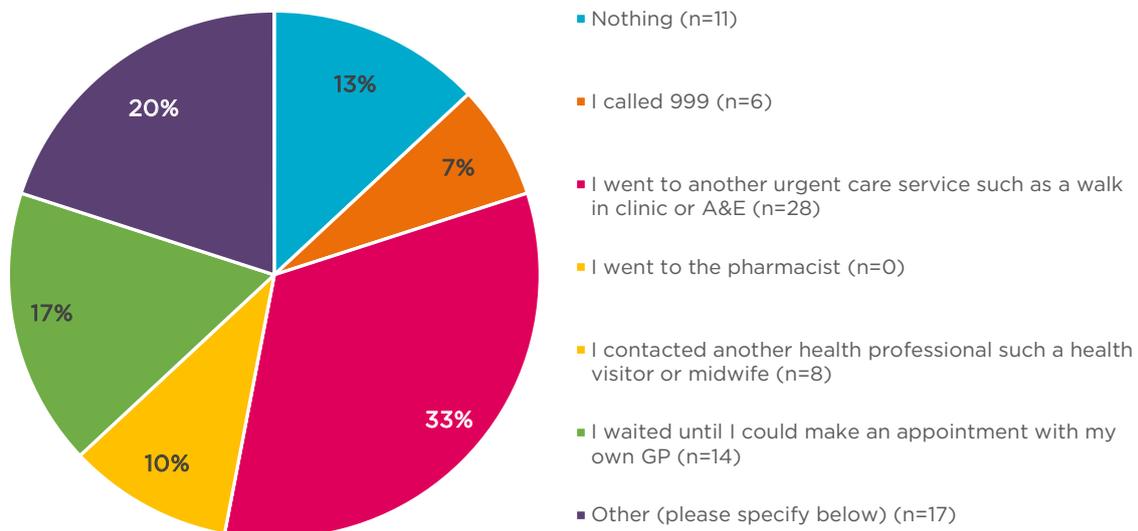
Graph 4. Advice or action received from NHS 111, by condition (n=992)



Ninety one percent (n=889) of parents or carers (who responded that it was necessary), stated they fully followed the advice or action received from NHS 111. This was similar across all four conditions. Of the 84 people who did not fully follow the advice (i.e. only partly followed it or did not follow it at all), a third (33%, n=28) stated the main action they took instead was to go to another urgent care service, such as a walk in clinic or ED. Seventeen percent (n=14) waited until they could make an appointment with their own GP and 13% (n=11) stated they did nothing more. Graph 5 below presents the full breakdowns of what parents or carers did if they did not follow the advice or action by NHS 111.

Graph 5. Breakdown of what parents or carers did if they did not follow the advice from NHS 111

Q14. What else did you do/do instead? (n=84)



The main reason parents or carers reported not following the advice received by NHS 111 was because they did not fully agree with it (39%, n=32). Almost a quarter of parents or carers (24%, n=20) stated that an alternative option became available, such as an out-of-hours pharmacist, and 19% (n=16) said it was not possible to follow the advice (e.g. they couldn't find appropriate care for other children) (Appendix 2 Frequency tables, Q15). Breakdowns by condition are not presented as the numbers of respondents per condition are too small to draw appropriate conclusions.

Overall, 84% (n=842) of parents or carers stated they definitely received what they needed from the NHS 111 service. Further, 80% (n=735) of parents or carers for whom it was applicable stated they would call NHS 111 again if they had the same problem at the same time of day or night in the future. A detailed report of findings is available in the Picker Institute report (Burger S & Witwicki C 2015).

Survey validation

Following implementation of the PREM, the validation study identified whether respondents completed all questions and whether there was scope to create a composite score to represent overall experience of the call. There was no evidence of questions being skipped when they were appropriate for a respondent and no indication of dropout from the questionnaire (detailed information can be found in Appendix 3 – Survey validation).

Part 2: Conclusions

This work package demonstrated that it was feasible to produce a PREM specific to parents and carers of children aged under 16 years, who have called NHS 111 on behalf of their child for one of four common conditions. The new parent questionnaire functioned well in enabling respondents to report their experience of using NHS 111. The survey validation findings mirrored those from the focus groups. There were no marked differences of experience of the call and the influence of this on the care pathway by condition about which they called, confirming there was no need to have individual surveys for each of the presentations.

The PREM was piloted in North West London and the following were considered as important factors as to whether parents or carers followed the advice given by NHS 111:

- The confidence in the information provided by NHS 111
- Trust and reassurance given by the NHS 111 health advisor
- How the user perceives advice and its relevance to their situation.

Overall experience of the call was shown to be associated with the extent to which parents or carers agreed with, and followed the advice from, the NHS 111 service.

This work compliments Part 1 of this report by investigating how the pathway of care that patients follow might depend on their experience of the NHS 111 service. The confidence in and accessibility to medical advice in relation to urgent care services is explored in Part 3 of this report.

Part 3: Online survey

Aims

Part 3 of the project aimed to:

- **Develop a population-based survey** for parents, carers and CYP to compliment the Picker Institute work package in investigating what these groups value in a telephone advice service such as NHS 111, and how the NHS 111 service can best be integrated into wider child health services
- **Implement the survey** among parents, carers and CYP to ascertain these views.

As described in the previous two work packages, the focus of this project has been to study the experience and wider healthcare utilization of children, young people and families who are in contact with NHS 111. From a policy perspective, one limitation of these work packages is that they only study the minority of CYP who are in contact with the NHS 111 services in any given year. There are currently few data available on attitudes and beliefs towards the NHS 111 at population level, or the degree to which CYP in contact with NHS 111 services differ from the general population (for example, in their healthcare beliefs or in their healthcare needs). Although formal investigation of this issue was beyond the scope of this project, the project group aimed to do some preliminary exploration of this area through an online survey of parents, carers and CYP.

Survey development

As many parents and carers either choose not to use the NHS 111 service or are not aware of it, this work package was proposed to gain population-based data on attitudes to using a telephone advice service, and the optimal role of such a service in different contexts.

Methods

The RCPCH project team identified key topics for the survey, which included:

1. The use of NHS services by CYP
2. Their and parent's or carer's confidence in healthcare professionals and in the NHS services for urgent care
3. Their preferences of which services to use in relation to their urgent care needs
4. Their views on accessing these services, and
5. Where parents or carers get advice about their child's urgent care.

These topics were then reviewed by stakeholders and categorised for inclusion into the draft survey. The draft survey was reviewed by a range of youth advisory and parent and carers groups on its content and phrasing. Following user feedback, two individual surveys were developed online via Survey Monkey, one for CYP, and the other for parents and carers. There was a second round of testing with youth advisory panels, parents groups defined by age and parental status, along with the Newcastle University evaluation partner to assess the flow, format and phrasing of the questions specific to each group. The final version of the parents and carers and CYP surveys are included in the Appendix 4 - CYP and Parents and Carers Online Survey.

Implementation of the survey

The surveys were disseminated via two routes. First, the RCPCH disseminated the questionnaire by advertising links to the Survey Monkey web page on the RCPCH **& Us** webpage, through RCPCH networks, and through partners at children's charities and think tanks via social media and twitter. In addition, the RCPCH worked with the North West London Champions to promote the survey via GP practices. In West London, the survey was sent to patients via email, posted on general practice websites and posted on the NWL Champions outpatient CYP Facebook page.

Results

Successful aspects of developing the online survey included:

- Gaining consensus within the project team on key questions to ask
- Positive feedback from lay reviewers that the survey was easy to understand and complete, and had face validity for exploring the relevant issues around attitudes to accessing NHS 111 and other NHS services
- No technical difficulties in disseminating the survey, survey completion by participants, or data extraction for analysis.

The original proposal identified that the major challenge of this work package would be obtaining a sufficient number of responses for analysis. Despite attempts to disseminate the survey through a range of networks and social media channels, a total of 53 completed surveys were received during the data collection period from March to June 2015.

A total of 46 parents and carers completed the online surveys; 45 surveys were completed via dissemination through the RCPCH networks and one survey was completed via dissemination through the NWL GP surgeries. A total of seven CYP completed the CYP version of the survey of which all were completed via the RCPCH networks.

There was a clear recruitment bias towards parents or carers with additional medical needs. For example, 40/46 (86%) of parents and carers reported that their child had a condition which required regular specialist care. Due to the small and unrepresentative sample, formal statistical analysis is not provided. However, descriptive findings are presented to illustrate the potential for this kind of survey to generate policy-relevant findings particularly if future studies are able to address the issue of recruiting a large, representative sample. Free-text sections of the survey are also reported.

Illustrative findings from parent and carers online survey

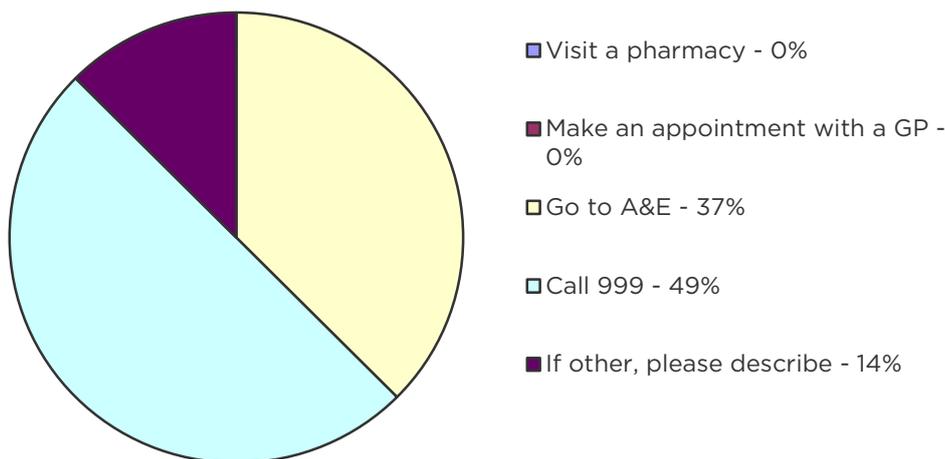
Over half of the parents and carers reported using NHS services more than once a month for their child's health (26/46 (56%)) and a high proportion of children were reported to have conditions that required regular specialist care (40/46 (87%)).

Parents and carers were asked to choose between GP, ED, 999, pharmacy, private healthcare, family and friends, NHS 111 or other as their preferred option for medical advice relating to their child's urgent care. Seventeen of forty six (37%) of respondents said that their preferred first choice in dealing with urgent care needs was the GP, followed by contacting family or friends (9/46 (19%)) and then by calling 999 (7/46 (15%)).

The majority of parents and carers would choose to call 999 (20/41 (49%)) or visit ED (15/41 (37%)) if their child had a breathing problem (graph 6). Fewer parents or carers would choose to visit ED (5/42 (12%)) or call 999 (1/42 (2%)) if their child had a fever (graph 7).

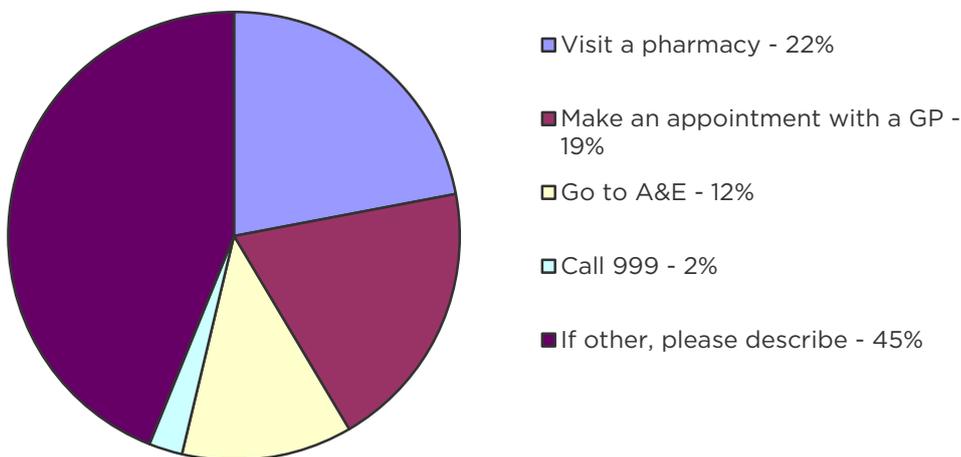
Graph 6. Parents and carers responses to an urgent concern about a breathing problem

If I had an urgent concern about my child’s breathing problem I would:



Graph 7. Parents and carers responses to an urgent concern about a fever

If my child had a fever (e.g. felt hot, or their temperature measured at least 38 celsius/100.4 fahrenheit) I would:



The majority of parents or carers would choose to visit a pharmacy (12/42 (28%)), GP (12/42 (28%)) or other (mostly ‘treat at home’ (17/42 (40%)) if their child had diarrhoea and vomiting. The least common options for this condition included calling 999 (0/42 (0%)) or visiting ED (1/42 (2%)). Similarly, parents or carers would choose to visit a pharmacy (17/42 (40%)), GP (14/42 (33%)) or other (mostly ‘treat at home’ 11/42 (26%)) if their child had constipation.

When asked about their confidence in the medical advice they received on managing urgent health problems from healthcare professionals, parents and carers felt very confident in medical advice from paramedics (31/42 (74%)), nurses (26/41 (63%)) and GPs (24/42 (57%)). Fewer participants

(14/41 (34%)) felt very confident in advice from a pharmacist, and a much lower proportion (3/41 (7%)) felt very confident in advice from a trained health advisor.

In response to how the NHS 111 call could be improved, parents and carers generally commented in the free text box that the service was not adapted to deal with complex conditions, *'My child's condition is too complex for a telephone service'* and *'They couldn't deal with my child's minor problem because of their complex health needs.'*

Parents and carers also explained the importance of feeling reassured by the health advisor, *'I felt that I had more knowledge than the person on the other end of the line'*, *'[It needed to be] less obvious that the person on the other end of the line was looking at a computer,'* and *'Had to go through a lot of standard questions most of which weren't relevant. I understand that a basic understanding of the problem has to be determined but it can be a concern when you are worried about a sick child.'*

When asked what did NHS 111 do well, again parents and carers particularly commented on the feeling of reassurance and informative advice; *'Prompt and reassuring that there is someone to talk to immediately,'* *'Very informative,'* *'When I did get through offered reassurance.'* Conversely, others did not report any positive aspects of care; these responses included: *'Not a lot. Gave the standard advice of take your child to hospital,'* *'nothing,'* and *'nothing much.'*

Part 3: Conclusions

There are currently few data on attitudes and beliefs towards the NHS 111 service at population level, or even on the how CYP who contact NHS 111 services may differ from the general population, for example, in their healthcare beliefs or in their healthcare needs. This work package showed that it was feasible to develop a survey with CYP, parents and carers, and other stakeholders that gather information about their attitudes to NHS 111 services and how they used them. There is a limitation that is apparent in this study in terms of its implementation, i.e. different strategies may be needed in the future to secure a sufficiently large and representative sample for this type of study. It is possible that a more ambitious strategy for dissemination through patient champion networks and social media could have been successful – especially if sustained over a longer period and at a time of year when young people were not pre-occupied with exam pressures. However, CYP may not necessarily feel motivated to complete a survey around their urgent care needs unless there is a 'pull factor'. The next phase of work may consider including incentives relevant to young people. Other options, including recruitment through school or hospital-based research networks could be considered.

Regarding the descriptive findings reported above, it would be more appropriate to view this work as an extended pilot project, which may inform future population-based surveys, rather than a completed study. If replicated in a more robust study, the differences described (for example in the preferred source of medical advice for different childhood conditions) could contribute to a deeper understanding of how pathways of care can work best in the interests of CYP.

Discussion

This report has explored the urgent care pathways and experiences of CYP, parents and carers calling NHS 111 with one of four common health conditions. The first work package showed that data from different NHS providers could be linked and analysed in ways that produce clinically important information about patient flow through NHS services. The second work package confirmed that a validated PREM could be produced, for NHS 111 services. Subsequently, the PREM was successfully piloted, revealing information about factors that may influence the parent or carer's choice of whether or not they follow the advice given by NHS 111. The third work package developed and piloted an online survey of parents' and carers' and CYP's views on accessing medical advice for urgent care needs. This was developed to provide a population basis for views on accessing medical advice. Two online surveys (one for parents and carers, and the other for CYP) were established but highlighted how future work could reach a wider population.

The linked data showed that NHS 111 calls were concentrated outside of traditional working hours, and that ED attendance was uncommon following contact with the telephone service, with only 7% of patients attending ED within three hours of the call. However, over 95% of the NHS 111 patients who subsequently attended ED had been advised by NHS 111 to follow up with their GP. A potential explanation of these findings arose from the qualitative research, with parents and carers most often reporting that the reason for calling NHS 111 was that it was out-of-hours for their GP. The relationship between NHS 111, other out-of-hours healthcare services and ED attendance could be explored further in future work.

Although most people reported a positive experience with NHS 111, a small subset of parents and carers (9% out of those who responded that it was necessary to contact NHS 111) reported not following the advice given about how they could either look after the health problem themselves or from where they should seek additional care. The main reasons given by parents or carers for not following the advice from NHS 111 were that they did not fully agree with it or that another option became available.

Further, the parents' and carers' experience of the NHS 111 call was associated with the extent to which parents or carers agreed with and followed the advice given. Those parents or carers who agreed with the advice tended to have a more positive experience than those who did not agree with the advice. Less positive experiences of the call were associated with the reports that the advice given was not appropriate and the advice given not being followed.

For some patients, the emergency department might have been the most appropriate point of care, and indeed in some cases symptoms might have deteriorated following the end of the NHS 111 call such that ED attendance was needed. It is also important to note the finding from the first phase of this project that demonstrated that many of the patients who attended St. Mary's ED did so of their own accord, without first calling NHS 111. Patients access urgent care through different routes and failure to take this into consideration can lead to a misunderstanding about how pathways in urgent care activity are used. Likewise, it is important to recognise that the care pathways that individuals follow will legitimately depend on their experiences of healthcare as well as clinical need.

The Five Year Forward View described models of care that could be used to support the improvement and integration of services (NHSE 2014). The remit of this project and future work in this area is in line with the aim of the urgent and emergency care vanguard sites to improve the co-ordination of urgent and emergency care services and to reduce pressure on A&E departments. The techniques showcased in this project could help shape the urgent care pathways for CYP particularly for common acute childhood conditions.

The conclusions from each of these three work streams show the value of establishing a prospective study that examines the diversity of patient flow and relates these pathways to the quality of care received at each point in the care pathway. Only by knowing what factors influence the decisions made by parents, carers and CYP about service use can commissioners and service providers design pathways of care that are efficient whilst still meeting patients' urgent care needs. The NHS is a complex system, and pathways will forever be evolving based partly on patients' experiences of using alternative healthcare services and their perceptions of the quality of care. By monitoring the evolution of these pathways using techniques similar to those developed in this report, commissioners can ensure that they are providing optimal care. This requires commissioners and service providers to assess the suitability and clinical appropriateness of the observed pathways while relating these to the needs of service users.

Recommendations

Compared to many other healthcare systems in the world, the NHS provides a large variety of urgent healthcare services. The question is whether the choices that people make regarding the use of urgent healthcare are leading to the highest quality, most effective and most efficient care possible, and if not how can patients and healthcare practitioners be better supported to make decisions that improve patient outcomes. This study has demonstrated some techniques that commissioners, urgent and emergency care vanguards, and service providers can use, which combine data analytics with the input of CYP, parents and carers.

Part 1: Data linkage

NHS 111 and the perceived difficulties of accessing in-hours and out-of-hours care

Further analysis could examine in greater detail whether NHS 111 call volumes are associated with perceived difficulties with accessing both in-hours and out-of-hours general practice care. For example, this work could relate call volumes to the results of the General Practice Patient Survey about the ease of reaching someone from the general practice by phone or how often patients are able to see their preferred GP.

Linking NHS 111 data with GP-in hours data

Although the current study was able to relate NHS 111 calls to subsequent emergency department and out-of-hours GP visits, data on 999 calls or in-hours GP services could not be examined. Likewise it was not possible to analyse a substantial number of NHS 111 calls that were labelled patient “unwell and less than 1 year old”. Further analysis could incorporate additional data to examine the patient pathway in more detail, as well as examining other symptoms than those considered in this report.

Seasonal influences on patient flow

The current study has found variations in NHS 111 call volumes over the course of the day and during the week, but future work could examine seasonal influences on patient flow more generally, for example as related to respiratory problems. Ideally, the design and commissioning of services would be able to anticipate fluctuations in the predicted need for healthcare specific to CYP.

Part 2: PREM

NHS 111 to develop a routine experience survey relevant to CYP

This project has demonstrated that it is feasible to measure the experience of parents and carers in relation to their child’s urgent care. This is important since the current NHS 111 satisfaction survey is not adapted specifically to report on the experience in relation to CYP urgent care.

Further investigation of linking PREM data with the routine data

The current study has demonstrated the feasibility of collecting systematic data on the caller experience of using NHS 111 services, utilising a validated PREM.

Although PREM respondents were asked about their subsequent use of healthcare services, within this study, the PREM data were not linked to the patients in the cohort of the routine dataset. This would have been challenging given that the differences in periods of sampling and there being no common patient identifier.

Future research could examine if and how self-reported outcomes or pathways differ from those indicated by the routine data sets. This could show the differences between parents' or carers' perceptions of the most appropriate care pathway for their child and those proposed in the clinical guidance associated with the each of the conditions. In turn this could inform commissioners about the most effective pathways that match clinical needs with patients experiences, and expectations.

This would mean that the complete patient journey from the contact with NHS 111 to the final conclusion of the episode of the patient's illness could be mapped and provide important information about what may suit patient's requirements for healthcare services.

Part 3: Online survey

Better engagement with CYP through the RCPCH networks

The poor response rates to the online survey highlight the difficulties of engaging parents, carers and CYP. The findings from the online survey work suggest that a more ambitious and better-resourced strategy for dissemination and recruitment through patient networks and social media may be required for future projects. This is an area of real importance when considering the utility of pathways of care from patient perspectives. Currently, the RCPCH is increasing the direction of its CYP participation and engagement to ensure that CYP are actively engaged in the College's outputs. For example, the RCPCH engagement collaborative will be an ideal platform to connect with external organisations to increase outreach and uptake.

To develop additional methods to improve survey recruitment, especially among younger audiences in addition to strengthening the approaches used to disseminate the online survey. Other routes should be considered for survey development, for example, recruitment through school or hospital-based research networks. Age-specific recruitment methods should also be considered, for example age-specific focus groups and signposting through mobile apps.

References

Armon K. et al. Determining the common medical presenting problems to accident and emergency departments. *Archives of Disease in Childhood*. 2001; 84: 390-392

Atlas of Variation in Healthcare for Children and Young People. Annex of the Annual Report to the ; Chief Medical Officer 2012. *Our Children Deserve Better: Prevention Pays*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_Anx_9.pdf [accessed June 2015]

Brogan C, Pickard D, Gray A et al. The use of out of hours health services: a cross sectional survey. *British Medical Journal* 1998; 316: 524

Burger, S. & Witwicki, C. 2015. *NHS 111: Patient Reported Experience Measure*. Picker Institute Europe (www.pickereurope.org)

College of Emergency Medicine 2013. *The drive for quality: How to achieve safe, sustainable care in our Emergency Departments? System benchmarks and recommendations*. 2013. Available at: <http://www.rcem.ac.uk/code/document.asp?ID=7030>). [accessed September 2015]

Cooper D, Arnold E, Smith G et al. The effect of deprivation, age and sex on NHS Direct call rates. *British Journal of General Practice* 2005; 55: 287-29

Cox, D.R & Oakes, D, 1984. *Analysis of survival data*, London: Chapman and Hall.

Deeny, S.R. & Steventon, A., 2015. Making sense of the shadows: Priorities for creating a learning healthcare system based on routinely collected data. *BMJ Quality & Safety*, 24, pp. 505-515.

Department of Health, (2012) *Total time spent in accident and emergency (pre-2011/12 Q2) and NHS England, A&E waiting times and activity (current)* [online] Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/194093/The-Quarter-2-2012_13_FINAL1.pdf [accessed: June 2015].

Gill PJ, Goldacre MJ, Mant D et al. Increase in emergency admissions to hospital for children aged under 15 in England, 1999-2010: national database analysis. *Archives of Disease in Childhood* 2013; 0: 1).

Intercollegiate Collegiate Committee for Standards for Children and Young People in Emergency Care Settings., 2012. *Standards for Children and Young People in Emergency Care Settings*. <http://www.rcpch.ac.uk/sites/default/files/page/Intercollegiate%20Emergency%20Standards%202012%20FINAL%20WEB.pdf> [accessed September 2015]

Health & Social Care Information Centre. *Accident and Emergency Attendances in England 2013 - 2014*. <http://www.hscic.gov.uk/searchcatalogue?productid=17200&q=title%3a%22accident+and+emergency+attendances%22&topics=0%2fHospital+care&sort=Relevance&size=10&page=1#top> [accessed September 2015]

Hendry SJ, Beattie TF and Heaney D. Minor illness and injury: factors influencing attendance at a paediatric accident and emergency department. *Archives of Disease in Childhood* 2005; 90: 629-633;

Knowles E, O’Cathain A, Turner J and Nicholl J. Awareness and use of a new urgent care telephone service, NHS 111: cross-sectional population survey. *Journal of Health Services Research and Policy* 2014; 19: 224-230.

NHS England 2013. *High quality care for all, now and future generation: Transforming urgent and emergency services in England- Urgent and Emergency Care Review End of Phase 1 Report. November 2013.* Available at: <http://www.nhs.uk/NHSEngland/keogh-review/Documents/UECR.Ph1Report.FV.pdf>). [accessed September 2015]

NHS England 2014. *NHS 111 Commissioning Standards.* June 2014. Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/06/nhs111-coms-stand.pdf>). [accessed September 2015]

NHS England 2014. Five year forward view. Available at: <https://www.england.nhs.uk/ourwork/futurehhs/> [accessed October 2015]

Maguire S, Ranmal R, Komulainen S et al. Which urgent care services do febrile children use and why? *Archives of Disease in Childhood* 2011; 96: 810-816.

McHale P, Wood S, Hughes K et al. Who uses emergency departments inappropriately and when- a national cross-sectional study using a monitoring data system *BMC Medicine* 2013; 11: 258.

O’Cathain A, Coleman P and Nicholl J. Characteristics of the emergency and urgent care system important to patients: a qualitative study. *Journal of Health Services Research and Policy* 2008; 13:19-25.

O’Cathain A, Knowles E, Turner J, et al. 2014. Acceptability of NHS 111 the telephone service for urgent healthcare: cross sectional postal survey of users’ views. *Family Practice* 31 (2) pp193-200.

Royal College of Paediatrics and Child Health, Imperial College Healthcare NHS Trust, NHS England. A Service Evaluation of the Pathways of Care for Children < 5 years through the NHS following contact with NHS 111: a pilot evaluation with a focus on children with fever. 2014 http://www.rcpch.ac.uk/system/files/protected/page/NHS111%20report%20e%20version_0.pdf [accessed June 2015]

Payne F and Jessopp L. NHS Direct: review of activity for the first year of operation at one site. *Journal of Public Health Medicine* 2001; 23: 155-158

Royal College of Paediatrics and Child Health, National Childrens Bureau and British Association for Child and Adolescent Public Health. Why Children Die: death in infants, children and young people in the UK. 2014 <http://www.rcpch.ac.uk/sites/default/files/page/Death%20in%20infants,%20children%20and%20young%20people%20in%20the%20UK.pdf> [accessed June 2015]

Royal College of Paediatrics and Child Health, 2010. To understand and improve the experience of parents and carers who need advice when a child has a fever (high temperature). http://www.rcpch.ac.uk/system/files/protected/page/Fever_report_FINAL2_0.pdf [accessed September 2015]

Rubin. D.B., 2010. On the limitations of comparative effectiveness research. *Statistics in Medicine*, 29(19), pp. 1991-1995. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20683890> [Accessed March 2013]

Sands R, Shanmugavadivel D, Stephenson T, Damian Wood. 2012 Medical problems presenting to paediatric emergency departments: 10 years on. *Journal of Emergency Medicine*; 29:379-382

Spencer, S.A. & Davies, M.P., 2012 Hospital episode statistics: improving the quality and value of hospital data: a national internet e-survey of hospital consultants. *BMJ open*, 2 (6).

Turner. J, O’Cathain. A, Knowles. E, et al., 2013 Impact of the urgent care telephone service NHS 111 pilot sites: a controlled before and after study. *BMJ Open*;3:e003451. doi:10.1136/bmjopen-2013-003451

Appendix 1 - NICE guidelines

- Fever - <https://www.nice.org.uk/guidance/cg160>
- Diarrhoea and vomiting - <https://www.nice.org.uk/guidance/cg84>
- Asthma - <http://www.nice.org.uk/guidance/qs25>
- Constipation - <http://www.nice.org.uk/guidance/cg99>

RCPCH care pathway for asthma: <http://www.rcpch.ac.uk/allergy/asthmarhinitis>

Appendix 2 - Picker frequency tables

Q9. What action or advice did you receive from NHS 111? (Q9)

	Frequency	Valid percent
An ambulance was called to my home	108	10.9
I was told to go to another urgent care service myself, such as a walk in clinic or A&E	232	23.4
The advisor made an appointment at an urgent care service on my behalf, such as a walk in clinic or A&E	202	20.4
I was advised to make an appointment with my own GP	77	7.8
I was advised to go to a pharmacist	9	.9
Nothing further, as I was assessed and given advice on how to look after the problem myself	328	33.1
Other (please specify below)	36	3.6
Total answered	992	100.0

Q15. If you did not fully follow the advice, why was this? (Q15) (those who did not fully follow the advice/action given by NHS 111)

	Frequency	Valid percent
I did not fully agree with the advice	32	38.6
I tried, but it did not work	12	14.5
An alternative option became available e.g. I found an out-of-hours pharmacist in another area	20	24.1
It was not possible to follow the advice e.g. I couldn't find appropriate care for other children	16	19.3
I did not fully understand the advice	3	3.6
Total answered	83	100.0

Appendix 3 - Survey validation

Basic item response frequencies

The overall proportions of respondents giving each answer option, and the proportions not responding, were examined. The proportions of missing responses were low throughout the questionnaire: there was no evidence of questions being skipped when they were appropriate for a respondent and no indication of dropout from the questionnaire. This is fairly typical of a telephone survey methodology.

Question 3 (When you first called, did the person you spoke to introduce themselves?) had a high proportion of non-evaluative 'can't remember' responses, which renders it less effective in differentiating levels of experience (and consequently affects the proposed composite score). The questionnaire appears to function well in enabling respondents to describe their experience of using the service. There is little item non-response and no indication of early dropout.

Composite score

In order to explore associations between parents'/carers' perceptions and experience of using the NHS 111 service and the resulting care pathway they chose, a composite score of respondents' "experience of the call" was created. Data for the following questions were entered into a factor analysis to examine whether responses to these questions may be explained by one or more common underlying dimensions of experience:

(Q3+) whether the first person parents/carers spoke to introduced themselves;

(Q4+) whether they felt the first person listened to them;

(Q5+) whether they had confidence and trust in the first person they spoke to;

(Q12+) whether parents/carers were involved as much they wanted in the decisions made about their child's care or treatment during the call.

In summary questions 3+, 4+, 5+ & 12+ measure a distinctive aspect of respondent experience and may be averaged to provide a composite score. Q6+ could also be used but this detracts from the reliability of the resulting composite, and because of the high proportion of missing scores on Q3+ the composite may be less consistent in practice. Detailed findings of the factor analysis conducted can be found in the Picker Institute's overall report.

The 'experience of the call' composite score proved capable of differentiating the experience of those who agreed with the advice, of those who did not think that they were clearly told why the advice they were given was appropriate, and of those who did not follow the advice given to them. Those parents or carers who agreed with the advice were associated with having a more positive experience than those who did not agree with the advice. Similarly, having a less positive experience of the call was associated with perceptions that the advice was not appropriate, and with not following the advice given.

Appendix 4 - CYP and parents and carers online survey

Introduction

The Royal College of Paediatrics and Child Health (RCPCH) are leading a project to look at urgent care services for children and how they could be improved. To do this we need to understand your views. We would like your views on NHS services and in particular your views on accessing medical advice.

The survey is **anonymous** and **confidential** and will take no longer than 15 minutes.

Who can take part?

Anyone aged 16 years and under in England.

Parental/Carer consent

Please ask your parent/carers for permission before you start the survey.

If you are under 12 years, please complete this with your parent/carers.

How will the information be used?

Our findings will be presented in a report to be shared with NHS England. All information will remain anonymous and all data will be stored securely and only accessible by the Children and Young People's Participation and Advocacy Team and the Project Manager at the RCPCH.

If you would like to know more about how this information will be used, or if you have any questions, please contact us via email at karina.pall@rcpch.ac.uk

As the survey is anonymous and confidential we won't be able to respond to any comments about individual experience. If you do have any concerns about the care you have received we suggest contacting your local PALS (<http://www.nhs.uk/chq/Pages/1082.aspx?CategoryID=68>)

About you

1. What is your gender?

- Female
- Male
- If other, please state:

2. How old are you?

- Under 12
- 13-14
- 15-16

There is also a **Parent & Carers version** of this survey. If you are a **Parent or Carer** and would like to complete this survey please follow the link - <https://www.surveymonkey.com/s/GVN38P5>

3. In the past year how many times have you used any kind of NHS services for your health?

- Regularly (more than once a month)
- Often (at least once a month)
- Occasionally (every few months)
- Rarely (less than every few months)
- Never
- I'd prefer not to say

4. In the past year what was the main reason for using the NHS?

- Preventative care (e.g. vaccinations, routine checks)
- Common problems (e.g. ear infection, tummy ache, toothache)
- Condition(s) which need regular GP care
- Condition(s) which need regular specialist care
- All of the above
- I'd prefer not to say
- Other, please describe

5. Please rank who you would go to for medical advice for your urgent care? (1=First choice 7=Last choice)

**This could be a problem which can't wait until the next day or the next appointment at your GP.
(It may be a problem which is upsetting or making you really worried).**

<input type="checkbox"/>	Pharmacist
<input type="checkbox"/>	GP
<input type="checkbox"/>	A&E
<input type="checkbox"/>	NHS 111
<input type="checkbox"/>	999
<input type="checkbox"/>	Family/ or friends
<input type="checkbox"/>	Private healthcare

What are you likely to do in these situations?

6. If you had an urgent concern about a breathing problem

- Visit a pharmacy
- Make an an appointment with my GP
- Go to A&E
- Call 999
- Tell my parent/carer
- Other, please describe

7. If you had a fever (i.e. felt hot, or had a temperature of at least 38 Centigrade/100.4 Fahrenheit)

- Visit a pharmacy
- Make an appointment with my GP
- Go to A&E
- Call 999
- Tell my parent/carer
- Other, please describe

8. If you had diarrhoea and vomiting

- Visit a pharmacy
- Make an appointment with my GP
- Go to A&E
- Call 999
- Tell my parent/carer
- Other, please describe

9. If you had constipation

- Visit a pharmacy
- Make an appointment with my GP
- Go to A&E
- Call 999
- Tell my parent/carer
- Other, please describe

10. How confident would you be in the medical advice from the healthcare professionals listed below?

	Very confident		Not sure		Not confident		I'd rather not say
GP	<input type="radio"/>						
Nurse	<input type="radio"/>						
Pharmacist	<input type="radio"/>						
Trained telephone adviser	<input type="radio"/>						
Paramedic	<input type="radio"/>						

11. Have you heard of NHS 111?

Yes

No

12. How did you first hear about NHS 111?

- At school
- Online
- TV
- Friends/family
- Word of mouth
- Other, please describe

13. Have you ever used NHS 111?

- Yes
- No

14. If yes, how many times?

- Once
- About 2 or 3 times
- More than 4 times
- I'd prefer not to say

15. In minutes, roughly how long was your most recent call to NHS 111?

- Less than 5 minutes
- Around 5-10 minutes
- Around 10-15 minutes
- Around 15-20 minutes
- Around 20-25 minutes
- Longer than 25 minutes

16. How satisfied did you feel at the end of the call?

- Very satisfied
- Quite satisfied
- Quite unsatisfied
- Very unsatisfied

17. How do you feel the call could have been improved?

(Please comment in the box)

18. What did NHS 111 do well?

(Please comment in the box)

19. What is your understanding of NHS 111?

(Please comment in the box)

20. How likely are you to recommend NHS 111 to friends or family?

- Very likely
- Likely
- Neither likely or unlikely
- Unlikely
- Very unlikely
- Not sure

About you

21. Which of these best describe your ethnic background?

- White (e.g. British, Irish, European)
- Mixed (e.g. White and Asian)
- Asian/Asian British (e.g. Indian, Pakistani, Bangladeshi)
- Black/Black British (e.g. West Indian, African)
- Chinese
- I'd prefer not to say
- Other, please describe

22. Where do you live?

23. Which of these is the main language spoken at home?

24. Would you be interested in knowing more and/or being involved in the RCPCH's work involving children and young people?

- Yes
- No

Thank you

Thank you for your time.

To register your interest in this project and/or the work we do with children and young people at the RCPCH, follow the link below.

http://www.rcpch.ac.uk/and_us

Introduction

The Royal College of Paediatrics and Child Health (RCPCH) are leading a project to look at urgent care services for children and how they can be improved. To do this we would like to understand the views of **parents and carers**. We would like your views on NHS services and in particular accessing medical advice for your child or children.

The survey is **anonymous** and **confidential** and will take around 15 minutes.

Who can take part?

Any parent or carer in England with a child under the age of 16. It doesn't matter if you or your children use the NHS regularly or not, we'd like to hear from **everyone**. We would particularly like to hear from parents and carers who have used NHS 111 for their children.

How will the information be used?

Our findings will be presented in a report to be shared with NHS England. All information will remain anonymous and data will be stored securely and only accessible by the members of the Children and Young People's Participation and Advocacy Team and the Project Manager at the RCPCH.

If you would like to know more about how this information will be used, or if you have any questions, please contact us via email at karina.pall@rcpch.ac.uk

As the survey is anonymous and confidential we won't be able to respond to any comments about individual experience. If you do have any concerns about the care you have received we suggest contacting your local PALS (<http://www.nhs.uk/chq/Pages/1082.aspx?CategoryID=68>)

About you and your children

1. What is your gender?

- Female
- Male
- Other

If other, please state:

2. How many children do you have?

- 1
- 2
- 3
- 4
- More than 4

3. How old are your children? (You can tick more than one option if your children are different ages)

- 0-5 years
- 6-10 years
- 11-16 years

4. How many children are you completing this survey for?

- 1
- 2
- 3
- 4
- More than 4

5. In the past year how many times have you used any kind of NHS service for your child's or children's health?

- Regularly (more than once a month)
- Often (at least once a month)
- Occasionally (every few months)
- Rarely (less than every few months)
- Never
- I'd prefer not to say

6. In the past year what was the main reason for using the NHS for your child's or children's healthcare?

- Preventative care (e.g. vaccinations, routine checks)
- Common problems (e.g. ear infections, tummy aches, toothache)
- Condition(s) which need regular GP care
- Condition(s) which need regular specialist care
- I'd prefer not to say
- If other, please describe

7. Please rank who would you go to for medical advice for your children's urgent care? (1= First choice 7= Last choice)

This could be a problem which can't wait until the next day or the next routine appointment at your GP.

(It may be a problem which is upsetting your child or making you really worried).

<input type="checkbox"/>	Pharmacist
<input type="checkbox"/>	GP
<input type="checkbox"/>	A&E
<input type="checkbox"/>	NHS 111
<input type="checkbox"/>	999
<input type="checkbox"/>	Family/friends
<input type="checkbox"/>	Private healthcare

What are you likely to do in these situations?

8. If I had an urgent concern about my child's breathing problem I would:

- Visit a pharmacy
- Make an appointment with a GP
- Go to A&E
- Call 999
- If other, please describe

9. If my child had a fever (e.g. felt hot, or their temperature measured at least 38 celcius/100.4 fahrenheit) I would:

- Visit a pharmacy
- Make an appointment with a GP
- Go to A&E
- Call 999
- If other, please describe

10. If my child had diarrhoea and vomiting I would:

- Visit a pharmacy
- Make an appointment with a GP
- Go to A&E
- Call 999
- If other, please describe

11. If my child had constipation I would:

- Visit a pharmacy
- Make an appointment with a GP
- Go to A&E
- Call 999
- If other, please describe

12. How confident would you be in the medical advice from the healthcare professionals listed below?

	Very confident		Not sure		Not confident		I'd rather not say
GP	<input type="radio"/>						
Nurse	<input type="radio"/>						
Pharmacist	<input type="radio"/>						
Trained telephone adviser	<input type="radio"/>						
Paramedic	<input type="radio"/>						

13. Have you heard of NHS 111?

Yes

No

14. How did you first hear about NHS 111?

- School
- Online
- TV
- Friends/family
- Word of mouth
- If other, please describe

15. Have you ever used NHS 111 for your child or children?

- Yes for **one** of them
- Yes for **two** of them
- Yes for **three** of them
- Yes for **four** (or more) of them
- No

16. If yes, how many times?

- Once
- About 2 or 3 times
- More than 4 times
- I'd rather not say

17. In reference to your most recent call, how long was it in minutes?

- Less than 5 minutes
- Around 5-10 minutes
- Around 10-15 minutes
- Around 15-20 minutes
- Around 20-25 minutes
- Longer than 25 minutes

18. How satisfied did you feel at the end of the call?

- Very satisfied
- Quite satisfied
- Quite unsatisfied
- Very unsatisfied

19. How do you feel the call could have been improved?

(Please comment in the box)

20. What did NHS 111 do well?

(Please comment in the box)

21. What is your understanding of NHS 111?

(Please comment in the box)

22. How likely are you to recommend NHS 111 to friends and family?

- Extremely likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Extremely unlikely
- Don't know

23. Which of these best describe your child's or children's ethnic background?

(You can tick more than one box if your children have different ethnic backgrounds)

- White (e.g. British, Irish, European)
- Mixed (e.g. White and Asian)
- Asian/Asian British (e.g. Indian, Pakistani, Bangladeshi)
- Black/Black British (e.g. West Indian, African)
- Chinese
- I'd rather not say
- If other, please describe

24. Where do you and your child or children live?

25. Which of these is the main language spoken at home?

Other (please specify)

26. Would you be interested in being involved with any further work to do with this project or the RCPCH's work involving Parents and Carers?

- Yes
- No

Thank you for your interest

Thank you for your time.

To register your interest in this project and/or the work we do with parents and carers at the RCPCH, please follow the link below:

http://www.rcpch.ac.uk/and_us



Published 2015.

Royal College of Paediatrics and Child Health
5-11 Theobalds Road, London, WC1X 8SH

The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).