

The Development of a Patient Reported Experience Measure for Paediatrics Patients (0-16 years) in Urgent and Emergency Care: Research Report

October 2012



Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

The Development of a Patient Reported Experience Measure (PREM) for Paediatrics Patients (0-16 years) in Urgent and Emergency Care

Research Report
October 2012

Funded and commissioned by the Department of Health



© 2012 Royal College of Paediatrics and Child Health
College of Emergency Medicine
Royal College of General Practitioners
Royal College of Nursing
London Ambulance Service
NHS Direct
National Patient Advice and Liaison Service Network
Picker Institute, Europe

Report prepared by

Ffion Davies

Jyotsna Vohra

Bridget Hopwood

This document should be referred to as follows

The Development of a Patient Reported Experience Measure (PREM) survey for children 0-16 years in Urgent and Emergency Care 2011. RCPCH, London

Royal College of Paediatrics and Child Health, College of Emergency Medicine, Royal College of General Practitioners, Royal College of Nursing, London Ambulance Service, NHS direct, National Patient Advice and Liaison service network, Picker Institute, Europe.

Contents

Foreword	4
Project group membership	5
Glossary	7
Executive summary	8
Chapter 1: Introduction	10
1.1 Patient experience in urgent and emergency care	
1.2 Patient participation	
1.3 Aims and objectives	
Chapter 2: Methodology	12
2.1 Governance and ethics	
2.2 Stages of development	
Chapter 3: Results	17
3.1 Literature search	
3.2 Focus groups	
3.3 Survey design	
3.4 Cognitive testing	
3.5 Pilot sites	
3.6 Data analysis	
3.6.1 Age distribution	
3.6.2 Completion of questions	
3.6.3 Problem scoring	
3.6.4 Question fatigue	
3.6.5 Survey structure	
3.6.6 Final refinement	
Chapter 4: Discussion	28
4.1 Key recommendations	
Chapter 5: Conclusions	31
Chapter 6: References	32
Appendices	33

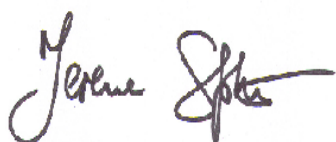
Foreword

It is with great pleasure that we recommend this patient survey to you, to be used by children, young people and their parents, regarding the services provided in NHS Urgent and Emergency Care (U&EC) settings. As all healthcare settings are striving to incorporate the views of their patients in order to improve their service, surveys are a way of collecting information. This survey has been tested in the U&EC setting, one which is often viewed as difficult for obtaining feedback (given that many patients are stressed, ill and in a hurry), and can be used by children themselves, a patient group where there are challenges and practical obstacles to obtaining their views.

What we do know is that children actually have a lot of views and good insight into their care. Their opinions were sought in designing this survey, to find out what is important to them, and the template survey has been tested successfully 'in real life'. Unlike previous surveys of this nature, this survey is evidence-based and was produced with a strict methodology. There are slight variations between the three suggested surveys, to make them meaningful for different settings: GP surgeries, ambulance services, and emergency departments/urgent care type centres.

The survey is a tool for service improvement. For an effective cycle of improvement, each locality may need to develop additional specific questions if the answers reveal a problem area. There is an implementation guide to assist in this evolving area of practice.

We wish to thank the children and families who participated in developing this survey. Your service will surely benefit your young patients as you listen and learn from their views.



Professor Terence Stephenson
President (2009-2012)
The Royal College of Paediatrics
and Child Health
Chair (2012-present)
Academy of Medical Royal Colleges



Dr Michael Clancy
President
The College of Emergency Medicine

Project group membership

Project board

Dr Ffion Davies, Consultant in Emergency Medicine, Project Clinical Lead
Dr Jyotsna Vohra, Science and Research Coordinator, Royal College of Paediatrics and Child Health
Mrs Bridget Hopwood, Picker Institute, Europe
Dr Nicholas Reeves, Department of Health (England)
Ms Helen Miller, Parents and Carers Advisory Group, Royal College of Paediatrics and Child Health
Ms Bharti Mepani, Children and Young People's Participation and Advocacy Manager, Royal College of Paediatrics and Child Health
Dr Christine Johnson, Royal College of General Practitioners
Dr Edward Wozniak, Paediatric Advisor to the Department of Health (England)
Ms Rebecca Lloyd, Children and Families branch, Department of Health (England)
Ms Lesley Wharton, NHS Direct
Ms Sue Harle, National Patient Advice Liaison Service manager
Mr Colin Way, Royal College of Nursing

Stakeholders

College of Emergency Medicine
NHS Direct
The Academy of Medical Royal Colleges
RCPCH Parent and Carer Advisory Group (PCAG)
Royal College of General Practitioners (RCGP)
Royal College of Nursing (RCN)
Picker Institute, Europe
Care Quality Commission (CQC)
Department of Health National Clinical Directors (NCDs) Dr Sheila Shribman, NCD for Children, Young People and Maternity Services and Prof Matthew Cooke, NCD for Urgent and Emergency Care
NHS Patient Advice and Liaison services (PALS)

Acknowledgements

We would like to thank the following:

Sites for piloting the survey once developed

Leicester Royal Infirmary Emergency Department, St Mary's Hospital London Emergency Department, Wycombe General Emergency Department, London Ambulance Service, East Midlands Ambulance Service Trust, Urgent Care Centre, Middlesbrough, Grovehill Medical Centre, Hemel Hempstead and Liverpool Urgent Care 24.

The children and young people, parents and carers who took part in developing and piloting the survey.

Bharti Mepani, for helping to organise and run the focus groups, and the RCPCH Research Projects Team.

Glossary

Cognitive testing

An iterative process whereby the understanding of the survey was tested on the target population (ie young urgent care patients and their parents) and constantly refined, until the wording, testing comprehension recall and volume of the questions was satisfactory.

Focus groups

Small groups of recent users of emergency healthcare were invited to give their opinions on what quality issues mattered to them in this setting. Children's and parents' views were recorded.

PREM

Patient Reported Experience Measure. This includes all types of ways of evaluating the patient's experience, including written or telephone surveys.

Urgent and Emergency Care

In this report, urgent and emergency healthcare is limited to same day unexpected/unplanned healthcare, such as GP surgery same-day urgent appointments, emergency calls to the ambulance service, attendance at emergency (A&E) departments and centres such as walk-in or urgent care centres for illness and injury.

Executive summary

Urgent and Emergency Care (U&EC) services in the UK are provided by a large range of organisations, including emergency departments, walk-in/urgent care type centres, general practices and ambulance services. Children make up at least 25% of all U&EC contacts/appointments, and they are often remembered as stressful experiences by both the parents/carers and children involved.

In all aspects of healthcare in the last few years, UK health policy has strengthened the input of patients themselves, in shaping health services in the future. UK hospitals have been measuring patient experience for adults in emergency departments for a number of years. The Department of Health (England) commissioned the Royal College of Paediatrics and Child Health to develop and pilot a tool to measure the paediatric U&EC experience in order to broaden the settings to incorporate multiple providers, following a report which demonstrated unsatisfactory patient experience for children under the age of five years with a fever accessing U&EC.

This project was steered by a project board led by the Royal College of Paediatrics and Child Health with representation from the College of Emergency Medicine, the Ambulance Service, Royal College of Nursing, Picker Institute, Europe, Royal College of General Practitioners, NHS Direct and the Patient Advice Liaison Service. The work was conducted September 2010 – March 2012.

Key aims of the project

- To develop a Patient Reported Experience Measure (PREM) ie survey, for use by paediatric patients, 0-16 years, using advice from children for completion by children.
- To test a paper-based survey in a range of U&EC settings.
- To ensure the survey can be used as the national standard by NHS Acute Trusts and Clinical Commissioning Groups in children's U&EC.
- To ensure that the survey can be adapted with ease to electronic or telephone formats, (eg web-based, touch screen, tablet device, etc).
- To ensure that the survey developed is useable outside of England, and the methodology for its development can be translated to a variety of paediatric healthcare settings, other than U&EC.

Methodology

- The project board oversaw the project, giving expert guidance and practical assistance.
- A full literature search of existing surveys related to paediatric U&EC yielded some useful information, but there was little evidence of tools designed with children to be completed by children.

- Focus groups were used to gain the views of children and their parents who had recent experience of U&EC.
- This was followed by cognitively testing the resulting survey on recent patients to ensure that it was fit for purpose, ie easy to complete and understand.

Key findings

- The survey was piloted in eight sites, representing all types of U&EC settings and found to be fit for purpose, with minor modifications.
- All key aims were achieved.

Recommendations

- This patient survey is the first of its kind, validated for use by paediatric patients, to test their experience of U&EC in all its settings.
- The final version of the survey (Appendix 1) can be used for service improvement alongside other national surveys for U&EC, in achieving Commissioning for Quality and Innovation (CQUINs) and Clinical Quality Indicators (CQIs), etc.
- Organisations should refer to the Implementation Guide to ensure successful data collection, analysis and service improvement. Other resources such as the full report and data analysis assistance are available on www.rcpch.ac.uk/uandecprem
- Picker Institute, Europe can be contacted for further statistical assistance with this survey, at different levels of support including the implementation of the survey if required.

1. Introduction

1.1 Patient experience in urgent and emergency care

U&EC services in the United Kingdom are provided by a range of providers including the ambulance service, emergency departments (accident and emergency department), General Practitioners (GPs) in- and out-of-hours, walk-in services, primary care call centres and NHS direct. For the purpose of this project and report all such same-day appointments are classified as Urgent and Emergency Care.

Most of the UK child population in any given year will require one of these services and will make up over a quarter of all visits to emergency departments. Children will often become sick faster than adults and have symptoms that are more difficult to define. At these times parents will often require urgent health advice and therefore same-day contact with a clinician. These episodes are often remembered as stressful by both the child and their parent/carer.

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

Following the Darzi Report *High Quality Care for All, The Final Report of the Next Stage Review*¹ where the importance of measuring the patients reported outcome and experience was identified; there has been growing interest into the concept of using the Patient Reported Experience Measure (PREM) as an indicator for measuring the quality/standard of healthcare being received by patients. The Darzi Report stated that by measuring the patients experience within the healthcare system we would be provided with the route for improving the quality of care that was being given. Following the Darzi Report the NHS Outcomes Framework² (2010) has further emphasised the need to measure the quality of care from the patients experience and the need to develop appropriate feedback systems to 'understand and improve the experience of patients'. More recently the Kennedy report³, Department of Health guidance⁴ and 'You're Welcome' quality criteria⁵, have highlighted the importance of developing tools that are suitable for the children themselves to use.

One of the eight Department of Health (England) U&EC Clinical Quality Indicators (CQIs) for emergency departments (Accident and Emergency), and one of the eleven CQIs for the ambulance service involves actively seeking information about patient/user experience⁶. In addition, NHS (England) Outcomes Framework includes people's experience of emergency services as one of its 27 improvement areas. Currently there are a number of questionnaires that exist to assess the patient perspective of different services within U&EC. Until this point there has not been a survey/tool that has looked at the patient perspective of the whole system⁷.

1.2 Patient participation

In general many of the surveys that do exist have been produced without taking the patients' point of view into account during the earlier stages of the design process; often they are created by the healthcare team alone. This has been particularly true for paediatric surveys, when occasionally the parents' views are incorporated into survey scope, but not the views of the children themselves.

Whilst these tools do collect some valid information, involving the child's point of view early in the design process would have improved relevance of topics covered, the design, and overall presentation⁸. Social researchers have been increasingly surveying children and young people to gain information on their attitudes and perspectives and they have reflected the fact that adults may not always understand what children want. Furthermore, the United Nations Convention of the Rights of the Child states that a child who is capable of forming his or her own views has the right to express these views freely and to have their views given due weight in accordance with their age and maturity⁹.

Through this study a project team including Picker Institute, Europe has developed and designed a survey for children and young people (up to 16 years) for use in U&EC organisations. The children and young persons' perspective was gained very early on in the design process and this is therefore a tool designed 'by the child for the child'. The pilot has demonstrated that the tool is reliable to use and can guide service improvement if implemented correctly. The resulting survey, its methodology and the implementation guide have been endorsed by the Royal College of Paediatrics and Child Health, the College of Emergency Medicine and the Department of Health (England). The methodology can easily be applied to other healthcare settings.

1.3 Aims and objectives

1. To develop a Patient Reported Experience Measure (PREM) for paediatric patients from 0-16 years who have been treated in the Urgent and Emergency Care setting. This includes emergency departments, same day GP appointments, ambulance calls, and visits to urgent care/walk-in centres.
2. To undertake focus group consultations with parents and carers and children and young people themselves, to derive the issues important to this group.
3. To use this information to design a survey, and to test it with the target user group of children and their parents ('cognitive testing'), to ensure it is fit for purpose.
4. To pilot the survey in U&EC settings and explore the feasibility of data collection methods and analysis.
5. To produce a well researched final survey, that has the possibility of being adapted for use in many formats including paper, web-based, touch screen, tablet device etc, for all NHS acute Trusts and Clinical Commissioning Groups to be able to use for children's U&EC.
6. To ensure that the survey is useable outside of England, and the methodology for its development can be translated to a variety of paediatric healthcare settings, other than U&EC.

2. Methodology

The PREM was produced through collaboration between the Research Projects Team at the Royal College of Paediatrics and Child Health (RCPCH) and the Children and Young People Research Team at the Picker Institute, Europe.

2.1 Governance and ethics

Ethical advice was sought from the National Research Ethics Services, who confirmed that the remit of this work would not require ethical approval.

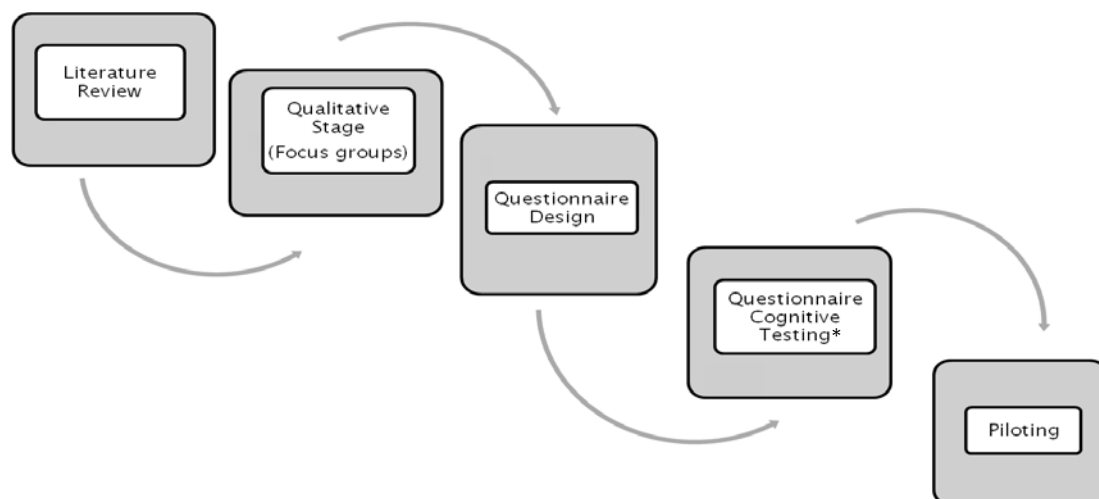
The project was overseen by the project board (see project membership) who met regularly throughout the duration of the project.

2.2 Stages of development

There were several stages of development, as shown in Figure 1, with continuous feedback integrated throughout the project.

Figure 1: Stages in survey development

Advisory board members involved at all stages – providing feedback and expertise



* Key stages involving end users, ie children and parents and carers

Stage 1: Literature review

An extensive literature search was carried out using the Embase and Medline databases.

Key search terms were used to identify relevant literature:

PREM
Patient reported experience measure
PROM
Patient outcome
Patient experience
Experience measures
Children's experience measures
Paediatric experience measures

Whilst the literature searching was not a systematic review it did identify key articles and was expanded to include a search of grey literature (literature including reports, that are produced and published by the government and its agencies). In addition, all stakeholders were contacted and asked to provide information and examples of any tools/surveys that they may have used or were aware of and the methodologies used to develop them. All information received indicated that on the whole surveys/tools that were used had not been evidence-based, taking into account the end users opinions in construct and design and ensuring suitability for use in a quality improvement cycle.

The Care Quality Commission coordinates the national patient surveys for England. Currently there is an adult emergency department survey that has been designed for national use. In addition, the Picker Institute, Europe has developed robust and validated paediatric in- and out-patient questionnaires. Information and knowledge gained from the development of these surveys were useful in developing the paediatric U&EC survey in terms of the development stages, question design, style and insight into issues in adult emergency care.

Stage 2: Qualitative stage focus groups

Four focus groups were held in order to ensure that the questions produced were evidence-based and covered the domains of service that are important to paediatric patients aged 0-16 years. The methodology for these groups has been well established by the Children and Young People's Participation and Advocacy Team of the RCPCH. Prior to the sessions a manual was developed to aid the facilitators and ensure that the views received were relevant to services in urgent and emergency care and would be taken into account (Appendix 2).

To gain a cross section of views and ages, more than one focus group was required and held, including one at the Grey Coats School, London. The participants for the remaining sessions were recruited by the Adkins Research Group, www.adkinsresearchgroup.com.

The sessions held and the age groups that they consisted of were:

- Grey Coats School, London, 12-13 years, female

- RCPCH, London, 5-8 years
- RCPCH, London, 16-18 years
- RCPCH, London, parents and carers of 0-8 year olds

A decision was taken early on to split the early and late teen years to ensure that all children and young people felt comfortable within the group and able to participate.

Through the focus group activities designed and as described in the facilitators guide it was possible to gauge the domains of healthcare which were important, and place them in order of importance to the participants. This provided clear indications on what the weighting of the questions with regards to topics or domains should be within the survey. The final tool was drafted using the information gained from the focus groups.

Stage 3: Survey design

The Project Board recommended from their experiences that the survey should be limited to four A4 sides maximum, and incorporate some free text boxes. It was also agreed that there should be two versions of the survey:

- 0-7 years (to be completed by the parent/carer but with as much input from the child as possible)
- 8-16 years to be completed by the child or young person by themselves

The age cut-off was recommended by the Picker Institute, Europe based on historical data that shows that the participation on the child's part increases significantly between the ages of seven and eight years. Language that would be suitable for a target reading age of eight years was used in designing the questions for the version to be completed by the children themselves, and similar questions with only slight differences in language were designed for the parent/carer version.

The survey was structured to ask the user about their experience of the U&EC setting as they travel through the healthcare episode chronologically, using 'reporting' style questions. It focuses on what happened as opposed to using a large number of general satisfaction questions. Historically, satisfaction questions have shown to generate positive results, which do not necessarily reflect the patients reported experience. They also do not discriminate well between countries, hospitals or units, and do not help to identify causes of dissatisfaction or priorities for quality improvement.

Stage 4: Cognitive testing of the survey

Once developed the survey was cognitively tested with a 'think out loud' methodology where a project facilitator takes the patient through the questions, recording their comments and questions, and providing clarification where needed. This tested whether the questions are easy to interpret and suitable for the target age range, the response options are not confusing and all answer options have been covered. It also tested the layout and ordering of the questions.

In total eleven cognitive tests/interviews were held. In each case either the participant or their child had accessed the urgent and emergency care services. The interviews were held in participants' homes or at Picker Institute, Europe offices and lasted approximately 30 minutes each.

An iterative process was established whereby the PREM was revised following the comments from each of the eleven cognitive tests and reviewed by members of the project team electronically prior to the next test. In total there were 15 iterations of the tool with version 15 being the one that was piloted.

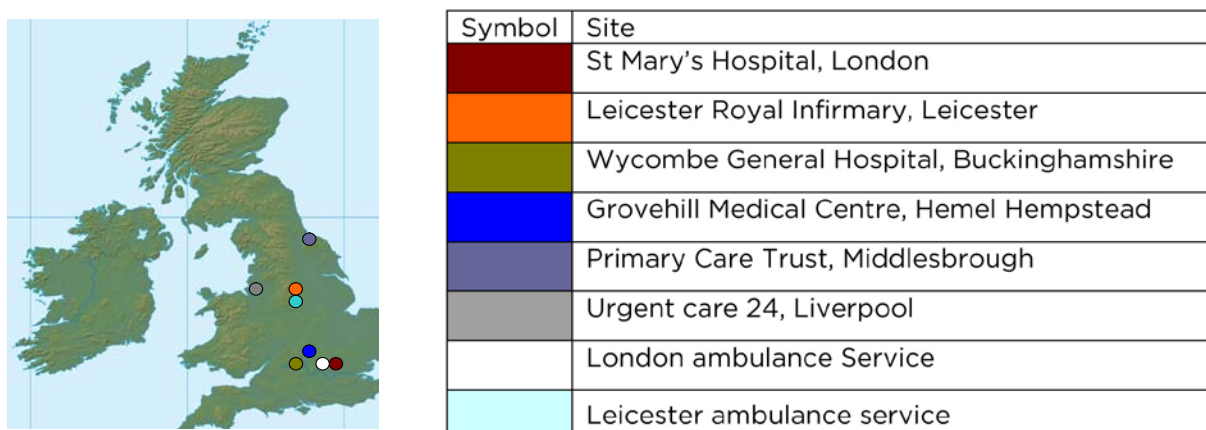
Stage 5: Piloting

Pilot sites were recruited to represent the commonest types of face-to-face U&EC settings and, where possible, a range of different socio-demographic and geographic areas of the UK, to improve the translation of results. The location of the pilot sites are shown in Figure 2.

Pilot sites were chosen to represent all types of urgent and emergency care services (see Table 2). Whilst NHS Direct were represented at the Project Board level, it was decided that the service would not be included in the pilot as they would only be able to conduct the piloting of the survey via the telephone and a call to NHS Direct would not necessarily result in a same-day appointment with a clinician.

The pilot was conducted May - July 2011 and each site was asked to run the pilot for a one month period or when 50 forms were completed, whichever happened first. The piloting was performed in a staggered start across all sites. Weekly contact was made with the site either by email or telephone to find out whether forms were being completed, verbal responses regarding the forms, whether more forms were required or further information was needed to aid and encourage patients to participate.

Figure 2: Showing distribution of the pilot sites through England



Stage 6: Data analysis

The completed forms were received at the RCPCH, London offices. The data was entered on an MS Excel spreadsheet that reflected which of the PREM tool versions were completed and the responses chosen.

Once the responses were coded and entered into the spreadsheet, data analysis was carried out by the Picker Institute, Europe. The data was analysed using the Statistical Package for Social Sciences (SPSS).

Stage 7: Survey refinement

As a result of the data analysis, minor changes were made, but the survey was found to be largely fit for purpose and the Project Board agreed a second piloting phase was unnecessary.

The minor changes which were made:

- A question was deleted as it overlapped with another.
- The two questions that appeared on the front page were moved alongside the other questions in the main body of the survey. This prevented them being unnoticed and therefore unanswered.
- Wording and formatting on the front of the surveys was standardised and the instructions were made clearer.

3. Results

All completed surveys were received by the Research Projects Team at the RCPCH and the responses logged in a database. Once the pilot was complete the datasheets that had been produced were sent to the Picker Institute, Europe's statisticians, who carried out detailed analysis using SPSS software. A log of the number of surveys sent to each pilot site, the number handed out and how many had been received was maintained at the RCPCH.

3.1 Literature search

A thorough literature search yielded very little material derived from children's own opinions; all paediatric surveys obtained by contacting several organisations and by publicising our request for existing surveys had been written by adults (usually staff, sometimes parents), with the exception of the paediatric in- and out-patients surveys designed by the Children and Young People Research Team at the Picker Institute, Europe.

3.2 Focus group results

The focus groups provided information about the key domains that children and young people were concerned about when they encountered the urgent and emergency care services. These sessions also provided an insight into the children's and young people's perception of the U&EC services. Overall the main themes that appeared to be represented were:

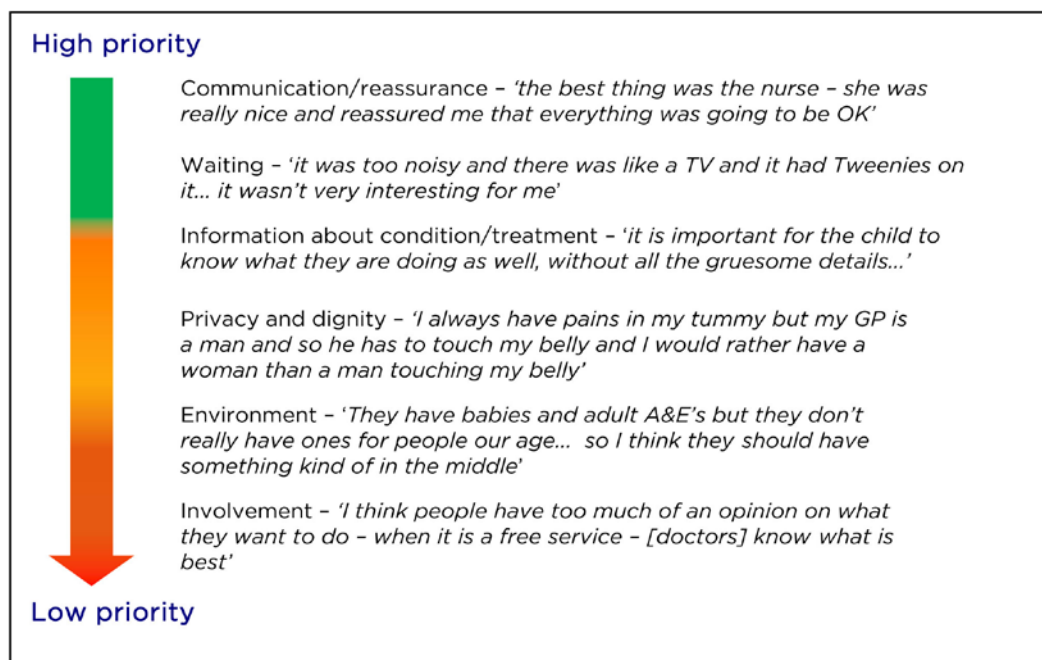
- NHS direct and web-based services were not considered to be a commonly used resource for urgent care
- Walk-in centres were thought to be for urgent, not emergency care, as opposed to Emergency departments, indicating a perceived difference between the two
- Ambulances were primarily considered to be intended for 'a life and death situation'
- U&EC services are a 'one off' and about the 'here and now'
- The main concerns were to be reassured about outcomes, would they have a speedy recovery, being 'made better' and being provided with for example pain control
- Respondents understood that waiting may be necessary for various reasons but did not think that the available activities to do during the wait were appropriate

3.3 Survey design

From the results of the focus groups it was possible to ascertain the key domains and the order of their importance to children (Figure 3). The most important factor when the children were in an emergency medical situation appeared to be reassurance that 'everything would be okay' and they were least concerned about being involved with decisions regarding their treatment in the U&EC context.

Other domains which were considered important were the length of waiting times and the facilities available, privacy and dignity, including the gender of the doctor (which was of particular importance to teenage girls), and the overall emergency care centre's environment. However all of these were rated as less important than reassurance and relief of symptoms.

The key domains and themes were used as a guide when developing the questions for the survey.



3.4 Cognitive testing results

The cognitive testing was an iterative process whereby the survey underwent continuous detailed feedback which was incorporated sequentially into each of the 11 versions. All families had relatively recent experience of using U&EC facilities. Table 1 shows the profile of the interviewees for the cognitive tests.

Table 1: Profiles of cognitive test interviewees

Respondent (child/parent)	Age of child (years)	Sex of child	Emergency care experience
Child	13	Male	Attended the ED* with a stubbed big toe.
Child	16	Female	Attended the ED after a blow to the head at school, suspected concussion.
Parent	2	Not collected	Attended the ED after falling off climbing frame.
Child	16	Female	Attended the ED after falling off a piggy-back ride and injuring their head.
Child	10	Male	Attended the ED after injuring foot on trampoline.
Parent	20 months	Female	Called ambulance after child fell down the stairs. Not transferred to hospital.
Child	12	Male	Attended the ED with asthma attack. Referred to larger hospital for overnight stay.
Child	13	Female	Attended the ED unwell with stomach pains. Admitted to ward for two weeks with perforated appendix.
Child	11	Female	Repeated ED visits due to undiagnosed discomfort and stomach/back pains. Admitted as an in-patient once.
Parent	5	Female	Paramedics called when hand was cut on a razor blade, went to the ED.
Child	15	Female	Went to the ED with mother after injuring finger during netball practice.

*ED - Emergency department in a hospital

Two types of survey were tested:

- For 0-7 year olds, to be completed by the parents and carers with as much input from the child as possible
- For 8-16 year olds to be completed by the patient themselves, with parental help if needed

The cognitive testing highlighted the need for separate versions of the survey for the ambulance service, GP surgery and out-of-hours/emergency department settings. This was to avoid confusion arising from multiple instructions to skip irrelevant questions, and to ensure that both questions and answers were relevant to the setting in order to maximise engagement.

Each survey type was very similar but avoided unnecessary questions, for example referring to phrases such as 'the waiting area' in the ambulance survey.

For complete details regarding the cognitive testing see Appendix 3. (Appendix 1 shows the final surveys, including the amendments that were made post-pilot.)

In total there were 31 different questions that were used across the three surveys and for the most part these overlapped (the full response profile of the questions and responses received can be seen in Appendix 4). The longest survey was the emergency department version that had 29 questions in total, and the shortest was the ambulance version that had 22. The GP version consisted of 27 questions.

3.5 Pilot site results

The pilot sites and the type of survey that was distributed to them is shown in Table 2.

Table 2: Pilot sites and setting

Setting	Site
Emergency departments and Urgent Care/Walk-in Centre services (E)	<ul style="list-style-type: none"> St Mary's Hospital, Londonⁱ Leicester Royal Infirmary, Leicesterⁱ Wycombe General Hospital, Buckinghamshireⁱⁱ Urgent Care 24, Liverpool, 5 centresⁱⁱⁱ: Old Swan, Huyton, Everton Road, Gaston and Aintree Urgent Care Centre, Middlesbroughⁱⁱⁱ
GP surgery urgent appointments (G)	<ul style="list-style-type: none"> Grovehill Medical Centre, Hemel Hempstead
Ambulance service (A)	<ul style="list-style-type: none"> London Ambulance Service East Midlands Ambulance Service

Key:

i = Emergency departments with specialist paediatric services

ii =Emergency departments not necessarily a paediatrician on site

iii =Out-of-hours

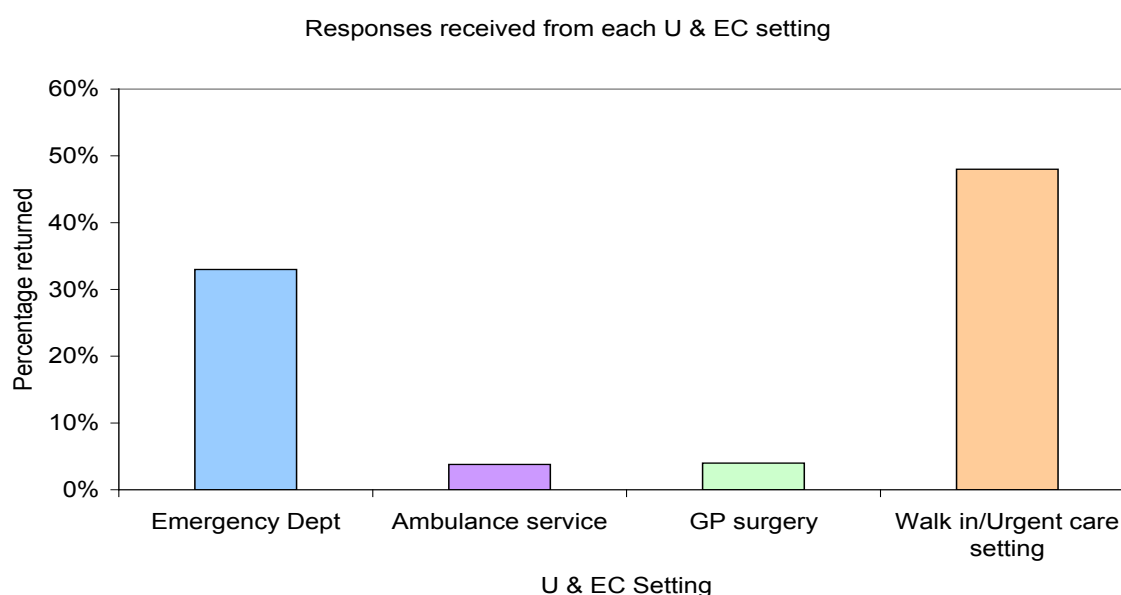
Completed surveys were returned from eleven of the twelve pilot sites across England (see Figure 4), which were chosen to represent the commonest types of face-to-face U&EC.

The London Ambulance Service (LAS) generated no returns for the survey; this was thought to be due to operational issues. Members of the LAS provided feedback to the project team that gave a greater understanding of the working pressures that may be involved with trying to use a survey tool within this area. Therefore consideration should be given towards the methods for collecting returns in various locations.

In total 1,430 surveys were distributed across all the sites. Of these 229 were returned to the Research Projects Team within the period of the pilot and a further four were returned after the pilot but were not counted during the analysis of the data. A remaining 535 were not handed out by the pilot sites. This provided an overall response rate of 26%. The best

response rate of 48% was achieved from the out-of-hours services and the lowest from the ambulance service and GP surgeries, 3.8% and 4% respectively (see Figure 4). By comparison, the national paediatric in- and out-patient surveys, which are conducted via postal surveys with two reminders, typically achieve a response rate of 35-40%.

Figure 4: Response rates from each type of U&EC setting



There was little difference in the ratio of parent's and carer's versions received (48%) to children's versions (52%) between the various sites, except for the ambulance service, where all responses were from the parents/carers.

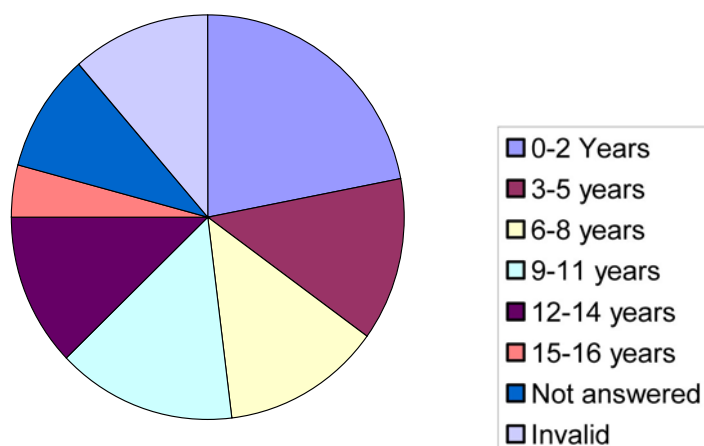
3.6 Data analysis

As the emergency department/urgent care centre survey consisted of the entire question set except one (ambulance survey Q3, specific to the ambulance service), and the majority of responses overall were received for this version (217/229), detailed analysis regarding questionnaire fatigue, problem scoring and the overall structure of the survey was carried out on this subset of surveys. Other results discussed represent the entire dataset.

3.6.1 Age of distribution

The age distribution for whom the completed survey refers to is shown in Figure 5 and closely resembles the age profile of U&EC paediatric attendances (Department of Health data). Of those returned 11.4% showed invalid ages, where the age of the parent was entered instead of the child's. In some cases this was due to the parent incorrectly receiving the 8-16 years version that asks 'how old are you?' as opposed to the one for younger children where the question is 'how old is your child?'

Figure 5: Age distribution of patients/families completed surveys



3.6.2 Completion of questions

With the exception of questions one and two on the emergency department/urgent care centre version of the survey most questions were answered well. These two questions were omitted in 35-81% of returns from these sites, it is believed due to an issue with the pagination.

The lowest response rate attained for an individual question was 82.5%. The questions for which there was a non-response rate of more than 10% are listed Table 3.

Table 3: Questions with greater than 10% unanswered rates

Question number	Question	Percentage unanswered
E12/G10/A7	Did you/your child feel safe/at ease with the staff they saw	16.6%
E17/G15/A11	After your emergency visit/care, what happened?	17.5%
E18/G16	Did someone tell you when you/your child could re-start your/ their usual activities, such as playing sport and returning to school	15.6%
E19/G17/A12	Did someone tell you what you should watch out for at home after your/your child's emergency care?	15.9%
E20/G18/A13	Did staff tell you what to do or who to contact if you were worried about anything after the emergency care?	15.0%
E22/G20/A15	Was the main reason for your emergency visit/care dealt with well?	12.2%

Key:

E - Emergency service version

G - GP practise version

A - Ambulance services

Due to the differences in the number of questions that were on each version of the survey and the fact that the same questions were not on all versions, it was not possible to carry out a 'point reached' analysis. The percentage of unanswered questions decreased for the final questions, where respondents were asked to provide answers regarding social demographics.

3.6.3 Problem scoring

Most patients are highly appreciative of the care they receive. However, it is evident that there is also a lot of scope for improving the patient experience. A simple summary score known as a 'problem score' has been applied to the results of the pilot. This was recommended by the Picker Institute, Europe and can help organisations identify where their patients think there is a problem or room for improvement regarding a specific aspect of care. They can also help monitor results over time and to show how an organisation compares to others. They can be used to target areas in need of attention to assist with making real quality improvements in the patient experience.

What do problem scores tell us?

The problem score shows the percentage of patients for each question who indicated in their response that a particular aspect of their care could have been improved. We have found this to be the simplest summary measure that focuses on quality improvement.

How are problem scores calculated?

Problem scores are calculated by combining the response categories that indicate room for improvement. For example, for the following question 'Do you think staff did everything they could to help you/your child?', the responses 'Yes, to some extent/sort of' and 'No' are combined to create a single problem score. Asterisks on the frequency tables (Appendix 4) indicate which responses have been combined to create the problem score for each survey question:

<u>E16/G14/A10. do you think staff did everything they could to help you / your child?</u>			
All patients	N	%	
Yes, definitely	181	79.0%	
* Yes, to some extent / sort of	27	11.8%	
* No	3	1.3%	
Don't know / can't remember	2	0.9%	
<i>Not answered</i>	16	7.0%	
Problem Score: 13.1%	229		

*options used to calculate problem score

How to interpret problem scores

As the name suggests, problem scores indicate where there may be a problem within a service that may need further investigation. It is useful to keep in mind that lower scores

reflect better performance. Where there are high problem scores, or scores that are high in comparison with other organisations, this area should be highlighted as a potential problem area that needs to be looked at further. Problem scores are an interpretation of the data recommended by the Picker Institute, Europe. Any comparisons made within an organisation (internal benchmarks, historic comparisons) or between organisations (external benchmarks) can be made using these scores.

Targeted questions

In the interests of accuracy, derived questions are used to produce more meaningful scores for questions that may not be applicable to all respondents, but are not preceded by a filter question. For example, question E1 asks about ambulance care, and a 'derived' question has been created (E1+) to exclude those who did not receive ambulance care. The purpose is to produce more precise indicators of where the problems lie within an organisation. A derived question is identified by a plus (+) symbol after the question number (see Appendix 4) and applies to questions E1+, E3+/G1+/A1+, and E13+/G11+/A8+.

In-depth analysis of the problem scoring was carried out for the emergency survey responses with the exceptions of questions one and two due to the large numbers that omitted these questions that were on the front of the form.

The remainder of the items were scored as dichotomous 'problem scores' according to the standard Picker Institute, Europe approach:

- 1 for response options deemed a problem
- 0 for others

Problem score means and standard deviations are reported in full in Appendix 5 and summarised in Figure 6. Item E21P that referred to how well the child had been looked after was relatively strongly skewed and also showed a limited variance, being almost universally rated as 'not a problem'.

3.6.4 Question fatigue

Full frequency tables were compiled to show the number of missing responses for each question, alongside data regarding the number of people who answered each question (this factor is important because as stated previously, questions one and two were frequently omitted due to oversight, as a result of pagination (they were on the front of the form)).

From this it was possible to calculate the point at which question fatigue began, called the 'point reached' analysis. Of those completing the survey 13% did not reach the final question and the cumulative percentage of incomplete questions begins to increase approximately a third of the way through the questionnaire at question 7 (Figure 7).

Figure 6: Item mean scores and standard deviations

Figure 2: Item mean scores and standard deviations

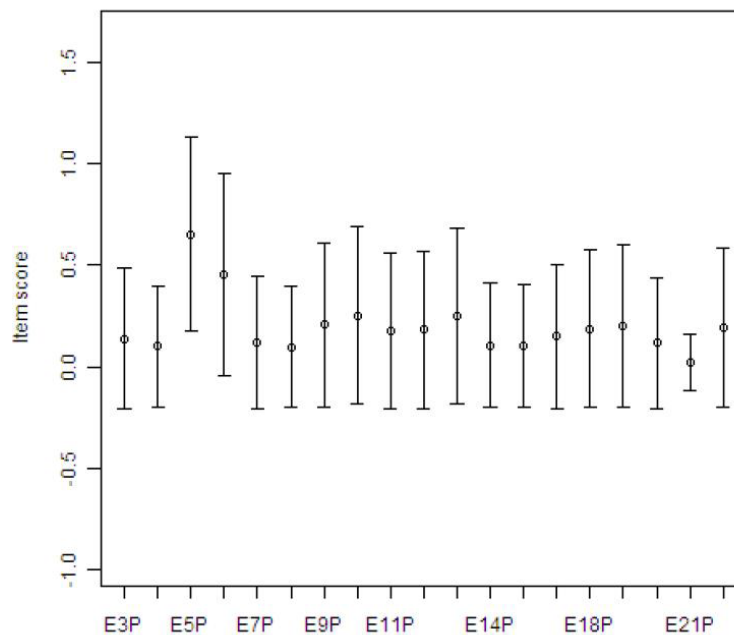
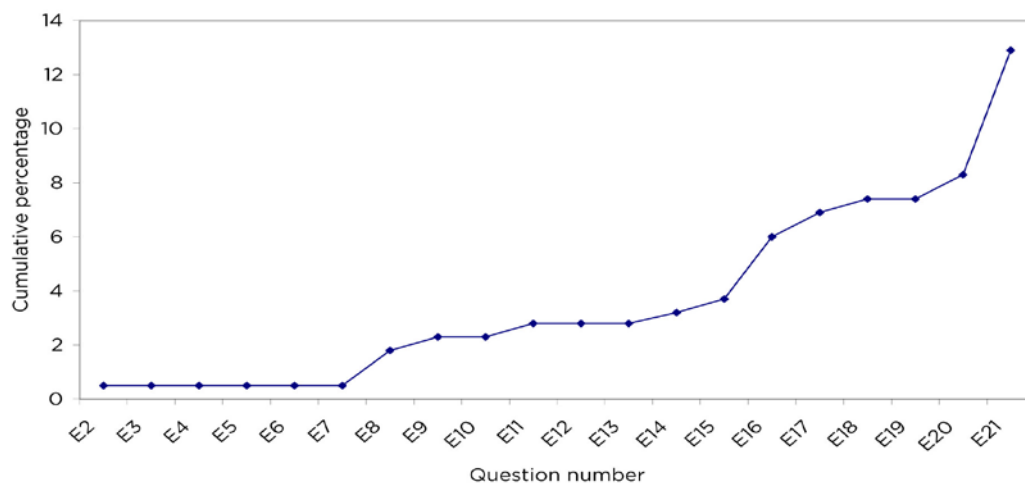


Figure 7: Cumulative percentage of number of responses provided



3.6.5 Survey structure

The relationship between items was examined by inter-item correlations. A version of the correlation coefficient that took account of the skewed score distributions was used. The table of inter-item correlations (Appendix 6) shows that correlations were quite varied, from strong to weak. One item – E8P – was weakly or negatively associated with all other items in the questionnaire. This item refers to cleanliness, whereas most other items relate more directly to clinical performance. E5P (asking whether there was enough for

the child to do when waiting) also showed a number of negative associations. Higher correlations were concentrated from E9P onwards, and these items are mostly about interactions with clinical staff. Overall, the pattern of correlations makes sense in relation to the item content.

The correlational structure was then explored using item cluster analysis¹⁰. The output is shown in Figure 8. The procedure links together first those questions whose responses are most closely related, then those clusters that are most closely related and so on. At each stage, two indications are given of the performance of the items in the cluster up to that point:

- Cronbach's alpha is an indication of the extent to which the items measure something in common. It is the most frequently quoted index of reliability, but is only accurate when certain conditions are met
- Revelle's beta is a lower limit for the reliability of the cluster, and is a better indication of the extent to which items measure the same underlying construct

The cluster diagram shows at each step the effect of merging items or clusters. This reveals one major cluster of eight items (C11). There is also a weaker cluster at C16 and smaller groupings at C14 and C5 (note that E8P is negatively related to this cluster). The effect of joining these four clusters is to weaken internal consistency. The questionnaire therefore probably measures four distinct underlying constructs, which relate to:

- (i) waiting and looking after the child
- (ii) interactions with clinical staff
- (iii) privacy and discharge information
- (iv) cleanliness and contact information

The last two of these appear to be weakly related, conceptually.

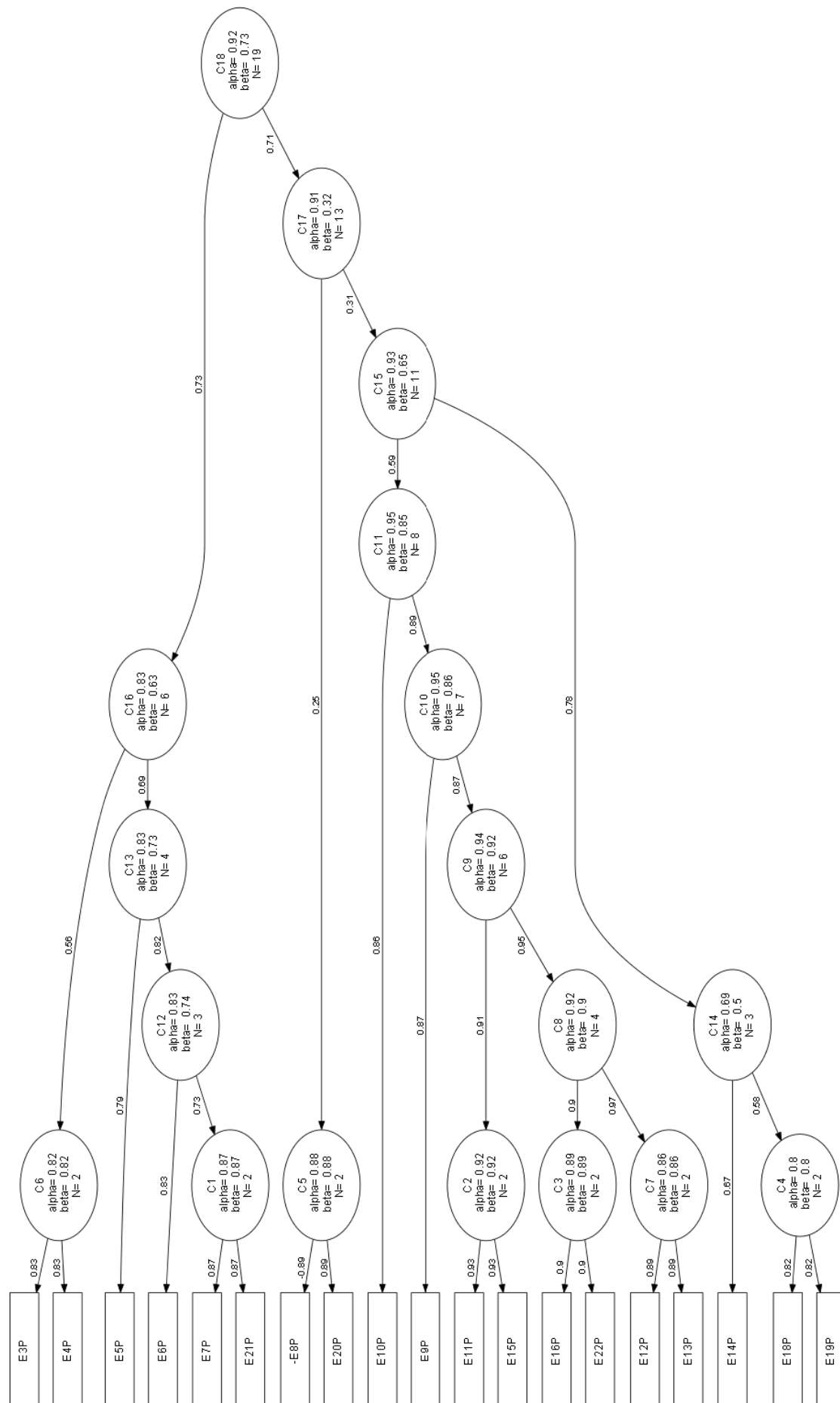
3.6.6 Final refinement of survey

After analysing the pilot results, the survey was deemed to be largely fit for purpose, without the need for major amendments or for a second piloted version.

The pagination issues relating to questions 1 and 2 of the emergency department/urgent care centre survey which resulted in the questions being overlooked were addressed by moving them onto the next page, alongside the other questions. One question was deleted due to overlap of concept with its neighbouring question.

The front page was reformatted to be simpler to understand and easier to read, and information which was only relevant to the RCPCH team was deleted. This was to ensure consistency of terminology between the three survey types and to allow space for individual organisations to enter their name and contact details.

Figure 8: Item structure through cluster analysis



4. Discussion

This report describes the development of an evidence-based tool for measuring the paediatric experience whilst utilising U&EC services. As patient experience becomes a significant part of service evaluation, and as U&EC healthcare contacts are one of the most frequent types of health contact for children, it is important that an easy-to-use, suitable survey, covering the most important quality measures, exists.

The age range of 0-16 years was chosen because this is how the majority of UK healthcare settings determine paediatric versus adult services. The choice of pilot sites represents the most commonly used U&EC services in the UK.

The methodology was deliberately designed with the intention of incorporating children's views, rather than those of healthcare professionals or parents in the final product. It could be argued that parents' opinions are also important, but in reality parents will assist their children in answering the questions. It is unlikely that parents' views will be overlooked as they are also free to enter further opinions in the free text boxes, and adults are surveyed separately in most U&EC settings.

The focus groups aimed to derive a set of values and priorities from children, followed by cognitive testing to ensure that the subsequent questions developed were fit for purpose. The experience which the Picker Institute, Europe brought from other areas of surveying was used in designing the tool.

Response rates were variable across the sites, however it was clear that championing at local level was necessary in all location types, and that the U&EC environment is very busy and does not naturally lend itself to survey completion, as demonstrated by the large variation in response (4-48%). The highest response rates were from urgent care centres and emergency departments, as compared with GP surgeries and ambulance services.

In order to achieve meaningful data for service improvement, the ideal number of responses required is between 50-100 returns of the form and this is what should be targeted when running the survey in each setting. The average response was 26% and this is felt to be valid for this setting and a high enough response rate for validity in terms of qualitative analysis for service improvement.

All pilot sites except the ambulance service used a similar method of a drop-box within the centre and the option of returning the survey with the pre-paid envelope at a later stage. For the ambulance services only the option of a pre-paid envelope was provided. Given the rapidly moving working environment of the ambulance journey, and the ambulant nature of despatch, it was perhaps unsurprising that return rates were low. The return rate improved with championing from respected clinicians, and motivation of staff during training sessions. Subsequent discussions post pilot with the ambulance service indicate that alternatives may be more fruitful such as a pick-up and drop-off box for surveys

being available at the emergency department reception area, with regular review of this box by the ambulance service in collaboration with the ED.

GP surgeries also had a low return rate. Post pilot discussions indicated that closer engagement with the practice manager and reception staff could have resulted in greater understanding amongst staff and some practical solutions to increasing survey hand-out.

Of the three emergency department sites a higher return rate was achieved when either a play specialist or a Patient Advisory Liaison Specialist (PALS) representative was available to champion the survey, provide support for the children and parents when answering the questions, and to encourage them to finish the survey and put it in the drop-box.

In response to this return rate, an implementation guide has been produced, for use alongside the survey. This covers practical issues such as the availability of a clear drop-box, the use of staff or volunteers to promote completion of the survey, the use of delayed returns with pre-paid envelopes or electronic options for data entry (touchscreens, tablet devices) or responses after the initial contact (email, website versions).

The final analysis tool of the survey showed that it is fit for purpose and this was also shown in the quality of the responses that were received. There appeared to be very few problems with comprehension or question fatigue. The main problem that did arise was the incorrect survey being provided: the 8-16 years version being provided to parents and the parental version to 0-7s. To correct this, the instructions and labelling on the front page were improved after the pilot. Following further suggestions both made during and post-pilot it was noted that the actual differences between the 0-7 years and 8-16 years versions of the survey were minimal and by combining the two, duplication could be removed.

All versions of the PREM indicated that some question fatigue began approximately two-thirds of the way through, however in the vast majority of completed forms all questions were completed. There were problems with completion of questions one and two in the ED survey, as they appeared on the front page and related to the ambulance service, therefore were not noticed. These questions were moved to the top of the first question page post-pilot. The completed and revised versions of the PREM are shown in Appendix 1.

We believe we achieved our aim of developing a survey which can be used outside England, as there is nothing which would exclude other NHS or U&EC settings. We also believe that the methodology of focus groups using recent child users of healthcare, cognitive testing and piloting, can be extrapolated to other healthcare services, such as other acute services or cancer care, and the questions from the PREM adapted to fit these settings.

The study was overall very successful in achieving its main aims however, due to limitations with regards to the ability to recruit more primary care sites and trial various

collection methods it was not possible to carry out analysis of a full cycle of re-surveying, which would lead to service improvement. This remains an implementation issue for each individual site.

4.1 Key recommendations

- The tool that has been developed is robust and able to highlight key areas of service improvement and should therefore be used as the primary method for gauging the paediatric patients' view of their experience in the emergency care setting
- The final versions of the PREM (appendix 2) are ready to be used in the relevant emergency care setting and Picker Institute, Europe can be contacted for any further statistical advice or implementation if required*
- In all areas where the PREM is being used it is imperative to have a local champion to promote the completion of the tool and provide support to the parents and carers where necessary
- The collection method for the completed forms should be considered and implemented accordingly including the use of smart phones and other electronic methods

* For each U&EC setting there are two versions of the PREM. The first for 0-7 year olds to be answered by the parents taking the child's opinion where age etc permits. The second is for 8-16 year olds to be answered by the child themselves. Where possible, it is recommended that these two versions are used side by side. If, however, the centre is unable to ensure the age-relevant version is handed out then a combined version is available. Please note that this version has not been cognitively tested and question ambiguities may arise as a result.

5. Conclusions

Via this collaborative project a robust tool to measure the experience of paediatric patients in U&EC has been developed. The survey has been designed from the principles of incorporating the views of children and has been thoroughly tested in the settings of emergency departments, GP surgeries, the ambulance service and walk-in/urgent care centres.

For success in implementation it is strongly recommended that organisations refer to the Implementation Guide (<http://www.rcpch.ac.uk/U&ECPREM>) and use the survey in a cycle of survey-improvement-resurvey for service improvement.

The survey can be used for immediate feedback using the paper format or can be tested for use in electronic formats, or mailed out (electronically or paper). A telephone version of the survey is currently being piloted by the Picker Institute, Europe.

6. References

1. Professor the Lord Darzi of Denham KBE. High Quality Care for all: NHS Next Stage Review Final Report. 2008. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
2. Department of Health E. NHS Outcomes Framework 2012/13. 2011. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700
3. Professor Sir Ian Kennedy. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. 2010. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
4. Department of Health E. Achieving equity and excellence for children. 2010. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
5. Department of Health E. 'You're Welcome': Quality Criteria for young people friendly health services. 2012. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813
6. Department of Health E. Clinical Quality Indicators in Urgent and Emergency Care (Accident and Emergency and Ambulance service). 2012. <http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Performancedataandstatistics/index.htm>
7. O'Cathain A, Coleman P, Nicholl J. Characteristics of the emergency and urgent care system important to patients: a qualitative study. *J Health Serv Res Policy* 2008;13:19-25.
8. Foster T, Maillardet V. Surveying young patients. *Emerg Med J* 2010;27:221-223.
9. United Nations. United Nations Convention on the Rights of the Child. 1989. http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-11&chapter=4&lang=en
10. Revelle W. Hierarchical Cluster Analysis and the Internal Structure of Tests. *Multivariate Behavioral Research* 14, 57-74.

Appendices

- 1. Final PREM surveys**
- 2. Facilitation guide**
- 3. Comments and amendments from cognitive tests**
- 4. Response profile for all questions used**
- 5. Problem scoring statistics for emergency department version**

Your Child's Urgent Appointment

What is the survey about?

This survey is about the emergency care and treatment that your child received at **the place where you were given the survey.**

Your views are very important to us to help find out how good the service was, and how we can make it better.

It is up to you whether you want to take part in this survey – you do not have to.

Who is the survey for?

The questions are for parents or carers of children aged under **8 years**.

Please try to answer on behalf of your child, if they are not old enough to answer the questions themselves.

If you are a child aged 8 or over please ask for the other version of this survey to fill in yourself

You do not need to say your name so please be honest. The answers you give us will help us improve our service.

Filling out the survey

For each question please tick ☒ clearly inside one box. For some questions you will be instructed that you may tick more than one box. Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. For some questions you will see a → **Go to Q** instruction next to a response. Where you see this, please follow the instructions and skip to that question.

Questions or help?

If you have any questions or need help, please ask a member of staff or phone:

It is up to you whether you want to take part in this survey – you do not have to.

All answers are confidential - nobody will know who said what!

SURVEY TYPE:

- **GP SURGERY**
- **PARENTS VERSION**

SITE NAME:

WAITING

1. How did you feel about **how long** you had to wait to be seen?

- 1 ☐ We did not have to wait at all → GO TO Q7
2 ☐ The wait was shorter than we expected
→ GO TO Q2
3 ☐ The wait was about as long as we expected
→ GO TO Q2
4 ☐ The wait was longer than we expected
→ GO TO Q2

2. While you were waiting, did someone keep you informed about **what was happening**?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, but this was not necessary
4 ☐ No, but we would have liked to have been told
5 ☐ Don't know / Can't remember

3. Was there **enough for your child to do** when you were waiting to be seen (such as toys, games and books)?

- 1 ☐ Yes, lots to do
2 ☐ Yes, some things, but not enough
3 ☐ There were things, but not for my child's age group
4 ☐ No
5 ☐ Can't remember / Did not notice
6 ☐ They had their own things to do

4. Was there **everything you needed** while you waited (such as food and drink, toilets, baby changing facilities etc.)?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need anything
5 ☐ Don't Know / Can't remember

5. Was your child looked after while you waited (for example, were they given pain relief, blankets or sick bowls if necessary)?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, they were not
4 ☐ No, but we didn't need anything
5 ☐ Don't know / Can't remember

6. How clean do you think the waiting area was?

- 1 ☐ Very clean
2 ☐ Quite clean
3 ☐ Not very clean
4 ☐ Not at all clean
5 ☐ Can't remember / Did not notice

YOUR CARE AND TREATMENT

7. Did the doctor (or nurse) that you saw **explain what they were doing** in a way you could understand?

- 1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need an explanation
5 ☐ Don't know / Can't remember

8. Did the doctor (or nurse) that you saw **explain what was wrong with your child** in a way you could understand?

- 1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don't know / Can't remember
5 ☐ They did not know what was wrong with my child

9. Do you feel that the staff did everything they could to **calm and comfort** your child and make them feel at ease?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not necessary

10. If your child was in pain, did the doctor (or nurse) do **everything they could to help** with their pain?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ My child was not in any pain

11. Were you and your child given **enough** privacy when they were being examined or treated?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, but we didn't mind
- 4 ☐ No, but we would have liked this
- 5 ☐ Don't know / Can't remember

AFTERCARE

12. After your urgent appointment, what happened?

- 1 ☐ My child was sent to hospital → GO TO Q16
- 2 ☐ We went home → GO TO Q13
- 3 ☐ We went to stay somewhere else → GO TO Q13

13. Did a member of staff tell you when your child could **re-start their usual activities**, such as playing sport or returning to school?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed

14. Did staff tell you what you should **watch out for** at home after your child's visit?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed
- 5 ☐ Don't know / Can't remember

15. Did staff tell you **what to do or who to contact** if you were worried about anything after your child's urgent appointment?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know / Can't remember

OVERALL

16. Overall, did you **receive enough information** about your child's condition and treatment?

- 1 ☐ Yes, enough information
- 2 ☐ Some, but not enough information
- 3 ☐ None, but I would have liked some
- 4 ☐ None, but I did not need any
- 5 ☐ They did not know what was wrong with my child

17. Overall, **how well do you think your child was looked after** during your visit?

- 1 ☐ Very well
- 2 ☐ Fairly well
- 3 ☐ Not very well
- 4 ☐ Not at all well

18. Was the main reason for your child's urgent appointment **dealt with well**?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No

19. Who was the main person who answered the questions on this survey?

- 1 ☐ Child (patient)
- 2 ☐ Parent / carer
- 3 ☐ Both child and parent/carer together

ABOUT YOUR CHILD

20. Is your child male or female?

1 ☐ Male



2 ☐ Female



21. How old is your child?

_____ years old

22. Which of these best describes your child's ethnic background? (Tick **ONE** only).

- 1 ☐ White (e.g. British, Irish, European)
- 2 ☐ Mixed (e.g. White and Asian)
- 3 ☐ Asian / Asian British (e.g. Indian)
- 4 ☐ Black / Black British
- 5 ☐ Chinese
- 6 ☐ Any other ethnic group

23. Which of these is the MAIN language spoken at home? (Tick **ONE** only)

- 1 ☐ English
- 2 ☐ Other European language
- 3 ☐ Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Chinese, Thai)
- 4 ☐ African language (such as Swahili, Hausa, Yoruba)
- 5 ☐ Other, including British Sign Language

ANYTHING ELSE TO SAY?

24. Was there anything you thought was **really good** about your urgent appointment?

25. Was there anything that **could have been better**?

Thanks very much for your help!

Your Urgent Appointment

What is the survey about?

This survey is about the emergency care and treatment that you received **at the place where you were given the survey.**

Your views are very important to us to help find out how good the services are and how we can make them better.

It is up to you whether you want to take part in this survey – you do not have to.

Who is the survey for?

The questions are for you to fill in if you are **8 years or older**. You may need your mum or dad or another adults help. That's fine.

If you are **under 8 years old please ask the staff for the other version of this survey.**

You do not need to say your name so please be honest. The answers you give us will help us improve our service.

Filling out the survey

For each question please tick ☒ clearly inside one box. For some questions you will be instructed that you may tick more than one box. Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. For some questions you will see a → **Go to Q** instruction next to a response. Where you see this, please follow the instructions and skip to that question.

Questions or help?

If you have any questions or need help please ask your parent or carer to telephone:

It is up to you whether you want to take part in this survey – you do not have to.

All answers are confidential - nobody will know who said what!

SURVEY TYPE:

- **GP SURGERY**
- **CHILD VERSION**

SITE NAME: _____

If you/your child are under 8 years old please ask the staff for the other version of this survey

WAITING

1. How did you feel about **how long** you had to wait to be seen?

- 1 ☐ I did not have to wait at all → GO TO Q7
2 ☐ The wait was shorter than I expected
→ GO TO Q2
3 ☐ The wait was about as long as I expected
→ GO TO Q2
4 ☐ The wait was longer than I expected
→ GO TO Q2

2. While you were waiting, did someone tell you **what was happening**?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No, but this was not needed
4 ☐ No, but I would have liked to have been told
5 ☐ Don't know / Can't remember



3. Was there **enough for you to do** when you were waiting to be seen (such as toys, games and books)?

- 1 ☐ Yes, lots to do
2 ☐ Yes, some things, but not enough
3 ☐ There were things, but not for my age group
4 ☐ No
5 ☐ Can't remember / Did not notice
6 ☐ I had my own things to do



4. Was there **everything you needed** while you waited (such as food and drink and toilets)?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ I did not need anything
5 ☐ Don't know / Can't remember

5. Were you looked after while you waited (for example, were you given pain medicine, blankets or sick bowls if you needed them)?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No, I was not
4 ☐ No, but I didn't need anything
5 ☐ Don't know / Can't remember

6. **How clean** do you think the waiting area was?

- 1 ☐ Very clean
2 ☐ Quite clean
3 ☐ Not very clean
4 ☐ Not at all clean
5 ☐ Can't remember / Did not notice



YOUR CARE AND TREATMENT

7. Did the doctor (or nurse) that you saw **explain what they were doing** in a way you could understand?

- 1 ☐ Yes, completely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ I did not need an explanation
5 ☐ Don't know / Can't remember



8. Did the doctor (or nurse) that you saw **explain what was wrong with you** in a way you could understand?

- 1 ☐ Yes, completely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ Don't know / Can't remember
5 ☐ They did not know what was wrong with me

9. Do you think that the doctor (or nurse) did everything they could to **calm and comfort** you?

- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed



10. If you were in pain, did the doctor (or nurse) do **everything they could to help** with your pain?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ I was not in any pain



11. Were you examined and treated **in private**?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No, but I didn't mind
- 4 ☐ No, but I would have liked this
- 5 ☐ Don't know / Can't remember



AFTERCARE

12. **After** your urgent appointment, what happened?

- 1 ☐ I was sent to hospital → GO TO Q16
- 2 ☐ I went home → GO TO Q13
- 3 ☐ I went somewhere else → GO TO Q13

13. Did someone tell you when you could **re-start your usual activities**, such as playing sport or returning to school?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed



14. Did someone tell you or your parent/carer what you should **watch out for** at home after your visit?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed
- 5 ☐ Don't know / Can't remember

15. Did staff tell you or your parent/carer **what to do or who to contact** if you were worried about anything after your urgent appointment?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know / Can't remember

OVERALL

16. Overall, did you or your parent/carer **receive enough information** about what was wrong with you and how to make it better?

- 1 ☐ Yes, enough information
- 2 ☐ Some, but not enough information
- 3 ☐ None, but I would have liked some
- 4 ☐ None, but I did not need any
- 5 ☐ They did not know what was wrong with me

17. Overall, **how well do you think you were looked after** during your visit?

- 1 ☐ Very well
- 2 ☐ Fairly well
- 3 ☐ Not very well
- 4 ☐ Not at all well



18. Was the main reason for your Emergency visit **dealt with well?**



- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No

19. Who was the main person who answered the questions on this survey?

- 1 ☐ Child (patient)
- 2 ☐ Parent / carer
- 3 ☐ Both child and parent/carers together

ABOUT YOU

20. Are you a girl or a boy?

- 1 ☐ A boy (male) 
- 2 ☐ A girl (female) 

21. How old are you?

_____ years old

22. Which of these best describes your ethnic background? (**Tick ONE only**). Please ask your parent or carer if you are not sure

- 1 ☐ White (e.g. British, Irish, European)
- 2 ☐ Mixed (e.g. White and Asian)
- 3 ☐ Asian / Asian British (e.g. Indian)
- 4 ☐ Black / Black British
- 5 ☐ Chinese
- 6 ☐ Any other ethnic group

23. Which of these is the MAIN language spoken at home? (**Tick ONE only**)

- 1 ☐ English
- 2 ☐ Other European language
- 3 ☐ Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Chinese, Thai)
- 4 ☐ African language (such as Swahili, Hausa, Yoruba)
- 5 ☐ Other, including British Sign Language

ANYTHING ELSE TO SAY?

24. Was there anything you thought was **really good** about your urgent appointment?

25. Was there anything that **could have been better?**

Thanks very much for your help!

Your Child's Emergency Care

What is the survey about?

This survey is about the emergency care and treatment that your child received at **the place where you were given the survey.**

Your views are very important to us to help find out how good the service was, and how we can make it better.

It is up to you whether you want to take part in this survey – you do not have to.

Who is the survey for?

The questions are for parents or carers of children aged under **8 years**.

Please try to answer on behalf of your child, if they are not old enough to answer the questions themselves.

If you are a child aged 8 or over please ask for the other version of this survey to fill in yourself.

You do not need to say your name so please be honest. The answers you give us will help us improve our service.

Filling out the survey

For each question please tick ☒ clearly inside one box. For some questions you will be instructed that you may tick more than one box. Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. For some questions you will see a → **Go to Q** instruction next to a response. Where you see this, please follow the instructions and skip to that question.

Questions or help?

If you have any questions or need help, please ask a member of staff or phone:

It is up to you whether you want to take part in this survey – you do not have to.
All answers are confidential - nobody will know who said what!

SURVEY TYPE:

- **AMBULANCE SERVICE**
- **PARENTS VERSION**

SITE NAME:

If you are a child aged 8 years or over please ask the staff for the other version of this survey

WAITING

1. How did you feel about **how long** you had to wait for the ambulance to arrive?

- 1 ☐ We did not have to wait at all
→ GO TO Q4
- 2 ☐ The wait was shorter than we expected
→ GO TO Q2
- 3 ☐ The wait was about as long as we expected
→ GO TO Q2
- 4 ☐ The wait was longer than we expected
→ GO TO Q2

2. While you were waiting, did someone tell you **what was happening?**

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, but this was not needed
- 4 ☐ No, but we would have liked to have been told
- 5 ☐ Don't know / Can't remember

3. While you were waiting, did someone tell you **what to do?**

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, but this was not needed
- 4 ☐ No, but we would have liked to have been told
- 5 ☐ Don't know / Can't remember

5. Did the paramedics/ambulance staff that you saw **explain what was wrong with your child** in a way you could understand?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ Don't know / Can't remember
- 5 ☐ They did not know what was wrong with my child

6. Do you think that the paramedics/ambulance staff did everything they could to **calm and comfort** your child?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed

7. If your child was in pain, did the paramedics/ambulance staff do **everything they could to help** with their pain?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ My child was not in any pain

CARE AND TREATMENT

4. Did the paramedics/ambulance staff that you saw **explain what they were doing** in a way you could understand?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ I did not need an explanation
- 5 ☐ Don't know / Can't remember

AFTERCARE

8. **After** your child's Emergency care, what happened?

- 1 ☐ My child went to hospital → GO TO Q11
- 2 ☐ My child went home / stayed at home
→ GO TO Q9
- 3 ☐ Other → GO TO Q9

9. Did someone tell you what you should **watch out for** at home after your child's care?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed
- 5 ☐ Don't know / Can't remember

10. Did staff tell you **what to do or who to contact** if you were worried about anything after your child's Emergency care?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know / Can't remember

OVERALL

11. Overall, did you **receive enough information** about your child's condition and treatment?

- 1 ☐ Yes, enough information
- 2 ☐ Some, but not enough information
- 3 ☐ None, but I would have liked some
- 4 ☐ None, but I did not need any
- 5 ☐ They did not know what was wrong with my child

12. Overall, **how well do you think your child was looked after** by the paramedics/ambulance staff?

- 1 ☐ Very well
- 2 ☐ Fairly well
- 3 ☐ Not very well
- 4 ☐ Not at all well

13. Was the main reason for your child's Emergency care **dealt with well**?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No

14. Who was the main person who answered the questions on this survey?

- 1 ☐ Child (patient)
- 2 ☐ Parent / carer
- 3 ☐ Both child and parent/carers together

ABOUT YOUR CHILD

15. Is your child male or female?

- 1 ☐ Male
- 2 ☐ Female



16. How old is your child?

_____ years old

17. Which of these best describes your child's ethnic background? (**Tick ONE only**).

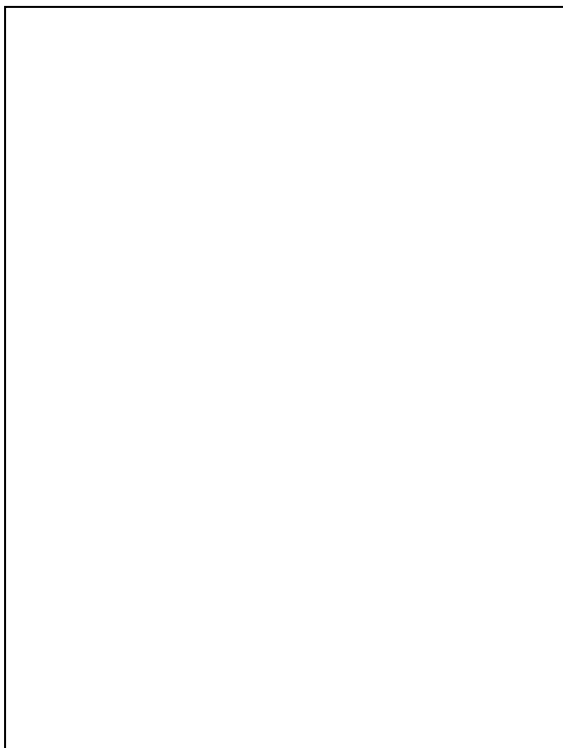
- 1 ☐ White (e.g. British, Irish, European)
- 2 ☐ Mixed (e.g. White and Asian)
- 3 ☐ Asian / Asian British (e.g. Indian)
- 4 ☐ Black / Black British
- 5 ☐ Chinese
- 6 ☐ Any other ethnic group

18. Which of these is the MAIN language spoken at home? (Tick ONE only)

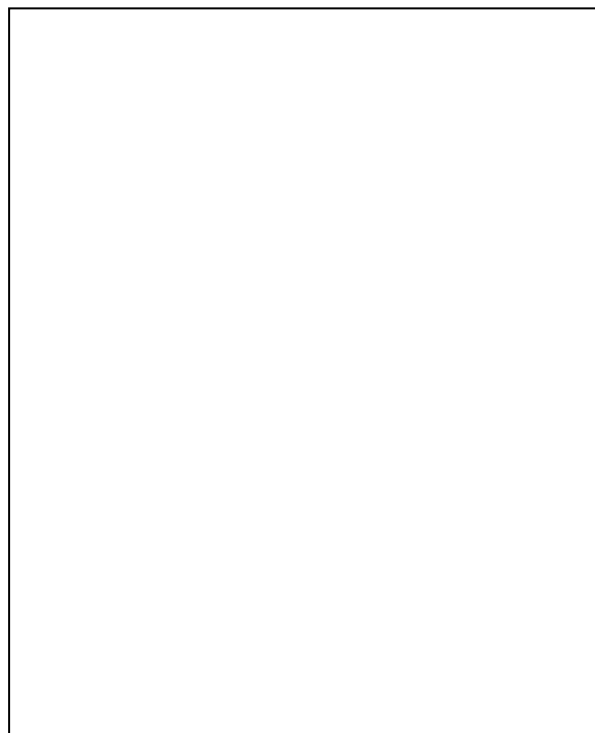
- 1 ☐ English
- 2 ☐ Other European language
- 3 ☐ Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Chinese, Thai)
- 4 ☐ African language (such as Swahili, Hausa, Yoruba)
- 5 ☐ Other, including British Sign Language

ANYTHING ELSE TO SAY?

19. Was there anything you thought was **really good** about your child's Emergency Care?



20. Was there anything that **could have been better**?



Thanks very much for your help!

Your Emergency Care

What is the survey about?

This survey is about the emergency care and treatment that you received **at the place where you were given the survey.**

Your views are very important to us to help find out how good the services are and how we can make them better.

It is up to you whether you want to take part in this survey – you do not have to.

Who is the survey for?

The questions are for you to fill in if you are **8 years or older**. You may need your mum or dad or another adults help. That's fine.

If you are **under 8 years old please ask the staff for the other version of this survey.**

You do not need to say your name so please be honest. The answers you give us will help us improve our service.

Filling out the survey

For each question please tick ☒ clearly inside one box. For some questions you will be instructed that you may tick more than one box. Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. For some questions you will see a → **Go to Q** instruction next to a response. Where you see this, please follow the instructions and skip to that question.

Questions or help?

If you have any questions or need help please ask your parent or carer to telephone:

It is up to you whether you want to take part in this survey – you do not have to.
All answers are confidential - nobody will know who said what!

SURVEY TYPE:

- **AMBULANCE**
- **CHILD VERSION**

If you/your child are under 8 years old please ask the staff for the other version of this survey

WAITING

1. How did you feel about **how long** you had to wait for the ambulance to arrive?

- 1 ☐ I did not have to wait at all → GO TO Q4
2 ☐ The wait was shorter than I expected
→ GO TO Q2
3 ☐ The wait was about as long as I expected
→ GO TO Q2
4 ☐ The wait was longer than I expected
→ GO TO Q2

2. While you were waiting, did someone tell you **what was happening**?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No, but this was not needed
4 ☐ No, but I would have liked to have been told
5 ☐ Don't know / Can't remember



3. While you were waiting, did someone tell you **what to do**?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No, but this was not needed
4 ☐ No, but I would have liked to have been told
5 ☐ Don't know / Can't remember

YOUR CARE AND TREATMENT

4. Did the paramedics/ambulance workers that you saw **explain what they were doing** in a way you could understand?

- 1 ☐ Yes, completely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ I did not need an explanation
5 ☐ Don't know / Can't remember



5. Did the paramedics/ambulance workers that you saw **explain what was wrong with you** in a way you could understand?

- 1 ☐ Yes, completely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ Don't know / Can't remember
5 ☐ They did not know what was wrong with me

6. Do you think that the paramedics/ambulance workers did everything they could to **calm and comfort** you?

- 1 ☐ Yes, completely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ This was not needed



7. If you were in pain, did the paramedics/ambulance workers do **everything they could to help** with your pain?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ I was not in any pain



AFTERCARE

8. After your Emergency care, what happened?

- 1 ☐ I went to hospital → GO TO Q11
2 ☐ I went home / stayed at home → GO TO Q9
3 ☐ Other → GO TO Q9

9. Did someone tell you or your parent/carer what you should **watch out for** at home after your Emergency care?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed
- 5 ☐ Don't know / Can't remember

10. Did staff tell you or your parent/carer **what to do or who to contact** if you were worried about anything after your Emergency care?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know / Can't remember

OVERALL

11. Overall, did you or your parent/carer **receive enough information** about what was wrong with you and how to make it better?

- 1 ☐ Yes, enough information
- 2 ☐ Some, but not enough information
- 3 ☐ None, but I would have liked some
- 4 ☐ None, but I did not need any
- 5 ☐ They did not know what was wrong with me

12. Overall, **how well do you think you were looked after** by the paramedics/ambulance workers?

- 1 ☐ Very well
- 2 ☐ Fairly well
- 3 ☐ Not very well
- 4 ☐ Not at all well



13. Was the main reason for your Emergency care **dealt with well**?



- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No

14. Who was the main person who answered the questions on this survey?

- 1 ☐ Child (patient)
- 2 ☐ Parent / carer
- 3 ☐ Both child and parent/carer together

ABOUT YOU

15. Are you a girl or a boy?

- 1 ☐ A boy (male) 
- 2 ☐ A girl (female) 

16. How old are you?

_____ years old

17. Which of these best describes your ethnic background? (**Tick ONE only**). Please ask your parent or carer if you are not sure

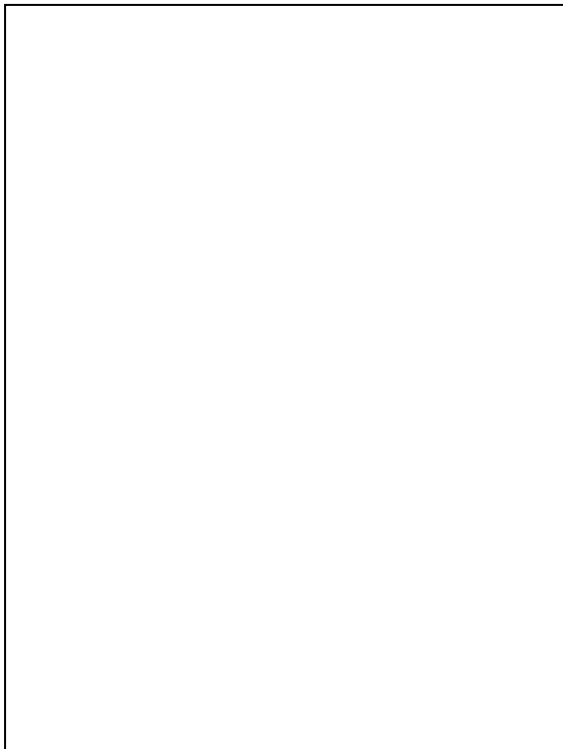
- 1 ☐ White (e.g. British, Irish, European)
- 2 ☐ Mixed (e.g. White and Asian)
- 3 ☐ Asian / Asian British (e.g. Indian)
- 4 ☐ Black / Black British
- 5 ☐ Chinese
- 6 ☐ Any other ethnic group

18. Which of these is the MAIN language spoken at home? (Tick **ONE** only)

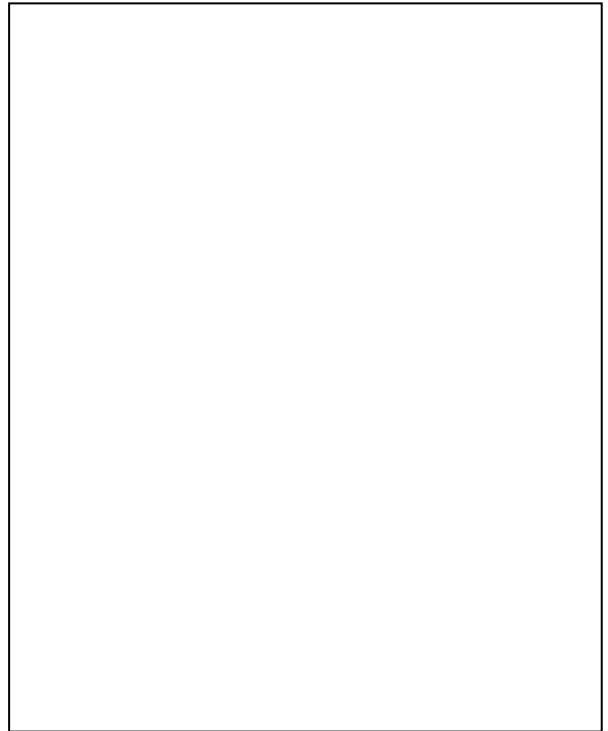
- 1 ☐ English
- 2 ☐ Other European language
- 3 ☐ Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Chinese, Thai)
- 4 ☐ African language (such as Swahili, Hausa, Yoruba)
- 5 ☐ Other, including British Sign Language

ANYTHING ELSE TO SAY?

19. Was there anything you thought was **really good** about your Emergency Care?



20. Was there anything that **could have been better**?



Thanks very much for your help!

Your Child's Emergency Care

What is the survey about?

This survey is about the emergency care and treatment that your child received at **the place where you were given the survey.**

Your views are very important to us to help find out how good the service was, and how we can make it better.

It is up to you whether you want to take part in this survey – you do not have to.

Who is the survey for?

The questions are for parents or carers of children aged under 8 years.

Please try to answer on behalf of your child, if they are not old enough to answer the questions themselves.

If you are a child aged 8 or over please ask for the other version of this survey to fill in yourself

You do not need to say your name so please be honest. The answers you give us will help us improve our service.

Filling out the survey

For each question please tick ☒ clearly inside one box. For some questions you will be instructed that you may tick more than one box. Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. For some questions you will see a → **Go to Q** instruction next to a response. Where you see this, please follow the instructions and skip to that question.

Questions or help?

If you have any questions or need help, please ask a member of staff or phone:

It is up to you whether you want to take part in this survey – you do not have to.
All answers are confidential - nobody will know who said what!

SURVEY TYPE:

- **EMERGENCY DEPARTMENT / WALK-IN CENTRE**
- **PARENTS VERSION**

SITE NAME: _____

AMBULANCE / PARAMEDICS

1. If an ambulance was called for your child, did the ambulance staff / paramedics **explain what was happening** in a way you could understand?

- 1 ☐ Yes, definitely → GO TO Q2
2 ☐ Yes, to some extent → GO TO Q2
3 ☐ No → GO TO Q2
4 ☐ An ambulance was not called → GO TO Q3
5 ☐ I can't remember → GO TO Q2

2. Overall, how well do you think the ambulance staff / paramedics looked after your child?

- 1 ☐ Very well
2 ☐ Fairly well
3 ☐ Not very well
4 ☐ Not at all well
5 ☐ Don't know / can't remember

WAITING

3. How did you feel about **how long** you had to wait to be seen?

- 1 ☐ We did not have to wait at all → GO TO Q9
2 ☐ The wait was shorter than we expected → GO TO Q4
3 ☐ The wait was about as long as we expected → GO TO Q4
4 ☐ The wait was longer than we expected → GO TO Q4

4. While you were waiting, did someone keep you informed about **what was happening**?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, but this was not necessary
4 ☐ No, but we would have liked to have been told
5 ☐ Don't know / Can't remember

5. Was there **enough for your child to do** when you were waiting to be seen (such as toys, games and books)?

- 1 ☐ Yes, lots to do
2 ☐ Yes, some things, but not enough
3 ☐ There were things, but not for my child's age group
4 ☐ No
5 ☐ Can't remember / Did not notice
6 ☐ They had their own things to do

6. Was there **everything you needed** while you waited (for example food and drink, toilets, baby changing facilities etc.)?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need anything
5 ☐ Don't know / Can't remember

7. Was your child looked after while you waited (for example, were they given pain relief, blankets or sick bowls etc if needed)?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, they were not
4 ☐ No, but we didn't need anything
5 ☐ Don't know / Can't remember

8. In your opinion, **how clean** was the waiting area?

- 1 ☐ Very clean
2 ☐ Quite clean
3 ☐ Not very clean
4 ☐ Not at all clean
5 ☐ Can't remember / Did not notice

CARE AND TREATMENT

9. Did the staff that you saw **explain what they were doing** in a way you could understand?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ I did not need an explanation
- 5 ☐ Don't know / can't remember

10. Did the staff that you saw **explain what was wrong with your child** in a way you could understand?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ Don't know / can't remember
- 5 ☐ They did not know what was wrong with my child

11. Do you think that the doctors and nurses did everything they could to **calm and comfort** you and your child?

- 1 ☐ Yes, completely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not necessary

12. If your child was in pain, do you think the staff did **everything they could to help** with their pain?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ My child was not in any pain

13. Were you and your child given **enough privacy** when they were being examined or treated?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, but we didn't mind
- 4 ☐ No, but we would have liked this
- 5 ☐ Don't know / Can't remember

AFTERCARE

14. After your Emergency visit, what happened?

- 1 ☐ My child stayed overnight in hospital
→ GO TO Q18
- 2 ☐ We went home
→ GO TO Q15
- 3 ☐ We went to stay somewhere else
→ GO TO Q15

15. Did a member of staff tell you when your child could **re-start their usual activities**, such as playing sport or returning to school?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed

16. Did staff tell you what you should **watch out for** at home after your child's visit?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ It was not necessary
- 5 ☐ Don't know / can't remember

17. Did staff tell you **what to do or who to contact** if you were worried about anything after your Emergency visit?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know / Can't remember

OVERALL

18. Overall, did you receive **enough information** about your child's condition and treatment?

- 1 ☐ Yes, enough information
- 2 ☐ Some, but not enough information
- 3 ☐ None, but I would have liked some
- 4 ☐ None but I did not need any
- 5 ☐ They did not know what was wrong with my child

19. Overall, **how well do you think your child was looked after** during their visit?

- 1 ☐ Very well
2 ☐ Fairly well
3 ☐ Not very well
4 ☐ Not at all well

20. Was the main reason for your Emergency visit **dealt with well?**

- 1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No

21. Who was the main person who answered the questions on this survey? **(TICK ONE ONLY)**

- 1 ☐ Child (patient)
2 ☐ Parent / Carer
3 ☐ Both child and parent/carer together

ABOUT YOUR CHILD

22. Is your child male or female?

- 1 ☐ Male
2 ☐ Female



23. How old is your child?

_____ years old

24. Which of these best describes your child's ethnic background? **(Tick ONE only)**

- 1 ☐ White (e.g. British, Irish, European)
2 ☐ Mixed (e.g. White and Asian)
3 ☐ Asian / Asian British (e.g. Indian)
4 ☐ Black / Black British
5 ☐ Chinese
6 ☐ Any other ethnic group

25. Which of these is the MAIN language spoken at home? **(Tick ONE only)**

- 1 ☐ English
2 ☐ Other European language
3 ☐ Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Chinese, Thai)
4 ☐ African language (such as Swahili, Hausa, Yoruba)
5 ☐ Other, including British Sign Language

ANYTHING ELSE TO SAY?

26. Was there anything you thought was **really good** about your child's Emergency Care?

27. Was there anything that **could have been better?**

Thanks very much for your help!

YOUR EMERGENCY CARE

What is the survey about?

This survey is about the emergency care and treatment that you received **at the place where you were given the survey.**

Your views are very important to us to help find out how good the services are and how we can make them better.

It is up to you whether you want to take part in this survey – you do not have to.

Who is the survey for?

The questions are for you to fill in if you are **8 years or older**. You may need your mum or dad or another adults help. That's fine.

If you are **under 8 years old please ask the staff for the other version of this survey.**

You do not need to say your name so please be honest. The answers you give us will help us improve our service.

Filling out the survey

For each question please tick ☒ clearly inside one box. For some questions you will be instructed that you may tick more than one box. Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. For some questions you will see a **→ Go to Q** instruction next to a response. Where you see this, please follow the instructions and skip to that question.

Questions or help?

If you have any questions or need help please ask your parent or carer to telephone:

It is up to you whether you want to take part in this survey – you do not have to.
All answers are confidential - nobody will know who said what!

SURVEY TYPE:

- **EMERGENCY DEPARTMENT / WALK-IN CENTRE**
- **CHILD VERSION**

SITE NAME: _____

AMBULANCE / PARAMEDICS

1. If an **ambulance** was called for you, did the ambulance staff/paramedics **explain what was happening** in a way you could understand?

- 1 ☐ Yes, definitely → GO TO Q2
2 ☐ Yes, sort of → GO TO Q2
3 ☐ No → GO TO Q2
4 ☐ An ambulance was not called → GO TO Q3
5 ☐ I can't remember → GO TO Q2

2. Overall, how well do you think the ambulance staff/paramedics looked after you?

- 1 ☐ Very well
2 ☐ Fairly well
3 ☐ Not very well
4 ☐ Not at all well
5 ☐ Don't know / can't remember



5. Was there **enough for you to do** when you were waiting to be seen (such as toys, games and books)?

- 1 ☐ Yes, lots to do
2 ☐ Yes, some things, but not enough
3 ☐ There were things, but not for my age group
4 ☐ No
5 ☐ Can't remember / Did not notice
6 ☐ I had my own things to do



6. Was there **everything you needed** while you waited (such as food, drink and toilets)?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No
4 ☐ I did not need anything
5 ☐ Don't know / Can't remember

WAITING

3. How did you feel about **how long** you had to wait to be seen?

- 1 ☐ I did not have to wait at all → GO TO Q9
2 ☐ The wait was shorter than I expected → GO TO Q4
3 ☐ The wait was about as long as I expected → GO TO Q4
4 ☐ The wait was longer than I expected → GO TO Q4

4. While you were waiting, did someone tell you **what was happening**?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No, but this was not needed
4 ☐ No, but I would have liked to have been told
5 ☐ Don't know / Can't remember



7. Were you looked after while you waited (for example, were you given pain medicine, blankets or sick bowls if you needed them)?

- 1 ☐ Yes, definitely
2 ☐ Yes, sort of
3 ☐ No, I was not
4 ☐ No, but I didn't need anything
5 ☐ Don't know / Can't remember

8. **How clean** do you think the waiting area was?

- 1 ☐ Very clean
2 ☐ Quite clean
3 ☐ Not very clean
4 ☐ Not at all clean
5 ☐ Can't remember / Did not notice



YOUR CARE AND TREATMENT

9. Did the doctors and nurses that you saw **explain what they were doing** in a way you could understand?

- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ I did not need an explanation
- 5 ☐ Don't know / Can't remember



10. Did the doctors and nurses that you saw **explain what was wrong with you** in a way you could understand?

- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ Don't know / Can't remember
- 5 ☐ They did not know what was wrong with me

11. Do you think that the doctors and nurses did everything they could to **calm and comfort** you?

- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed



12. If you were in pain, did the doctors and nurses do **everything they could to help** with your pain?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ I was not in any pain



13. Were you examined and treated **in private**?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No, but I didn't mind
- 4 ☐ No, but I would have liked this
- 5 ☐ Don't know / Can't remember



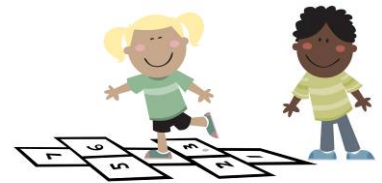
AFTERCARE

14. **After** your Emergency visit, what happened?

- 1 ☐ I stayed overnight in hospital [→ GO TO Q18](#)
- 2 ☐ I went home [→ GO TO Q15](#)
- 3 ☐ I went to stay somewhere else [→ GO TO Q15](#)

15. Did someone tell you when you could **re-start your usual activities**, such as playing sport or returning to school?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed



16. Did someone tell you or your parent/carer what you should **watch out for** at home after your care?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This was not needed
- 5 ☐ Don't know / Can't remember

17. Did staff tell you or your parent/carer **what to do or who to contact** if you were worried about anything after your Emergency visit?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know / Can't remember

OVERALL

18. During your visit, did you or your parent/carer **receive enough information** about what was wrong with you and how to make it better?

- 1 ☐ Yes, enough information
- 2 ☐ Some, but not enough information
- 3 ☐ None, but I would have liked some
- 4 ☐ None, but I did not need any
- 5 ☐ They did not know what was wrong with me

19. Overall, **how well do you think you were looked after** during your visit?

- 1 ☐ Very well
- 2 ☐ Fairly well
- 3 ☐ Not very well
- 4 ☐ Not at all well



20. Was the main reason for your Emergency visit **dealt with well?**

- 1 ☐ Yes, completely
- 2 ☐ Yes, sort of
- 3 ☐ No

21. Who was the main person who answered the questions on this survey?

- 1 ☐ Child (patient)
- 2 ☐ Parent / carer
- 3 ☐ Both child and parent/carer together

ABOUT YOU

22. Are you a girl or a boy?

- 1 ☐ A boy (male)
- 2 ☐ A girl (female)



23. How old are you?

_____ years old

24. Which of these best describes your ethnic background? (**Tick ONE only**). Please ask your parent or carer if you are not sure

- 1 ☐ White (e.g. British, Irish, European)
- 2 ☐ Mixed (e.g. White and Asian)
- 3 ☐ Asian / Asian British (e.g. Indian)
- 4 ☐ Black / Black British
- 5 ☐ Chinese
- 6 ☐ Any other ethnic group

25. Which of these is the **MAIN** language spoken at home? (**Tick ONE only**)

- 1 ☐ English
- 2 ☐ Other European language
- 3 ☐ Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Chinese, Thai)
- 4 ☐ African language (such as Swahili, Hausa, Yoruba)
- 5 ☐ Other, including British Sign Language

ANYTHING ELSE TO SAY?

26. Was there anything you thought was **really good** about your Emergency visit?

27. Was there anything that **could have been better?**

Thanks very much for your help!



Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

FACILITATORS BRIEFING GUIDE

PROJECT: TO DEVELOP EVIDENCE BASED URGENT AND EMERGENCY CARE-SPECIFIC PATIENT-REPORTED EXPERIENCE MEASUREMENT (PREM) FOR CHILDREN AND YOUNG PEOPLE TO ASSESS AND IMPROVE THEIR PATIENT CARE.

JANUARY 2011

Bharti Mepani, Children and Young People's Participation & Advocacy Manager, RCPCH

CONTENTS

INTRODUCTION	3
FACILITATORS BRIEFING GUIDE	4
FACILITATORS BRIEFING GUIDE PURPOSE.....	4
PURPOSE OF THE FOCUS SESSIONS	4
PRINCIPLES OF CHILDREN AND YOUNG PEOPLE’S PARTICIPATION	5
FOCUS SESSION PROGRAMME.....	11
FOCUS SESSION METHOD	11
FOCUS SESSION ACTIVITIES.....	12
ACTIVITY A – WHAT DOES URGENT & EMERGENCY CARE MEAN?.....	13
ACTIVITY B – WHAT IS IMPORTANT ABOUT THE U&EC HEALTH SERVICE CHILDREN AND YOUNG PEOPLE RECEIVE? ILLUSTRATIONS AND EXPERIENCES	14
ACTIVITY C– STORY BOX	15
ACTIVITY D – 0-----10 CONTINUUM.....	16
DIAMOND RANKING	17
DOCUMENTATION	20
YOUR ROLE AS A FACILITATOR.....	21
CONTACT DETAILS	23
APPENDIX	24
EXAMPLE OF THE INFORMATION SHEET & CONSENT FORM FOR PARTICIPANTS.....	24
EXISTING U&EC EVIDENCE ANALYSIS.....	28
REFERENCES	31

INTRODUCTION

The **Royal College of Paediatrics and Child Health (RCPCH)** is developing evidence-based Urgent and Emergency Care-Specific Patient-Reported Experience Measurement (PREM) for children and young people to improve their patient care. The PREM, once developed and piloted will inform the Department of Health (DH) Urgent and Care Division and the Children and Families Division, the College of Emergency Medicine (CEM) and the RCPCH of a set of indicators to assess and improve U&EC health services experienced by children young people and where relevant their parents/carers. This is a groundbreaking project that will develop PREM specifically designed for children and young people to influence U&EC improvement transformation.

A Project Board consisting of representatives from the above organisations has been established to govern the project, chaired by RCPCH. A project team has been established to implement the project, managed by RCPCH and working closely with the Picker Institute Europe, an independent healthcare research charity.

FACILITATORS BRIEFING GUIDE

Facilitators Briefing Guide Purpose

The Facilitators Briefing Guide has been developed to ensure the safe, meaningful and ethical participation of children and young people to influence the design of an urgent and emergency care- specific patient-reported experience measurement (PREM) for children, young people and their parents/ carers. The Facilitators Briefing Guide takes into account the limited existing relevant evidence available and the limitations of the overall project design, including time constraints.

A series of focus sessions will be held with a diverse group of children and young people aged between 5-18 years, across England to capture their experience of Urgent and Emergency Care Services (A&E, NHS Walk-in Centres, Urgent Care centres, Minor Injury Units and Ambulance services) and primary care settings such as GPs and out-of-hours (OOH) service, and their recommendations to improve patient care. In the context of this project and its limitations the focus sessions will take into account individual episodes of care as opposed to U&EC pathways. The project defines U&EC as: ***any unplanned or unscheduled visit to a health care professional.***

Whilst, the Project Board recognises Parents/ Carers play an instrumental role in relation to children and young people's experience of U&EC Health Services, this project will primarily focus on capturing the direct experience of children and young people and a specific focus session may be designed, where appropriate to ascertain additional information required from the parent/ carer perspective.

Purpose of the Focus Sessions

Focus sessions will be held with diverse groups of children and young people aged between 5-18 years, across England to:

- ❖ Enable children and young people influence the development of a U&EC PREM specifically designed for children and young people.
- ❖ Understand children and young people's experience of using a U&EC health service
- ❖ Identify areas of importance for children and young people in an U& EC setting
- ❖ Highlight issues from children and young people's perspective about U&EC standards
- ❖ Explore the critical questions children and young people would ask to review U&EC settings
- ❖ Reaffirm/ or challenge existing evidence on what children and young people find important in the U&EC setting.

Principles of Children and Young People's Participation

'Children and young people are not only beneficiaries of a health service but key stakeholders influencing the quality and delivery of their health service.'

Bharti Mepani, Children and Young People's Participation & Advocacy Manager, RCPCH

The following information has been extracted from the RCPCH document: Not Just a Phase, Guidance on Children and Young People's Participation in Health Services, 2010:

- ❖ Participation is about having the opportunity to express a view, influence decision-making and achieve change. Children and young people's participation is an informed and willing involvement of all children and young people, including the most marginalised and those of different ages and abilities, in any matter concerning them either directly or indirectly. (Save the Children, 2005).
- ❖ Participation is defined as the process by which individuals and/or groups of individuals can influence the decision making process and bring about change
- ❖ Participation involves a continuum from involvement of individual young people in decisions affecting their daily life to the engagement of large groups of young people in making strategic decisions about the use of substantial healthcare resources
- ❖ Children and young people's right to participate in matters affecting their lives is laid out in the United Nations Convention on the Rights of the Child (UNCRC), a legally binding International convention.

The following key principles and values underpin the participation of children and young people:

- Ethical issues surrounding children and young people's participation
- Honesty and transparency
- Health and safety
- Confidentiality
- Consent
- Safeguarding children and young people
- A positive environment
- Issues of communication
- Equality and diversity

Ethical issues

There are inevitable imbalances in power and status between adults and children. An ethical approach is needed for children and young people's participation to be meaningful. In the

context of this research it is important to remember that healthcare is a human right, that children and young people have a right to access the highest quality of standard of healthcare attainable (UNCRC article 24) and the right to be heard in matters affecting their lives (UNCRC, article 12). There is the risk of facilitating focus sessions that are tokenistic, pay lip service and reinforce existing patterns that prevent children and young people from accessing quality health services. It is important that the [principles within this guide are considered to ensure the safe, meaningful and ethical participation of children and young people. Expectations amongst all stakeholders in the project must be explored and consensus on key issues agreed early on to support effective planning for the meaningful participation of children and young people.

Honesty and Transparency

Clear policies are needed right from the start detailing the objectives, limitations, expected outcomes – (where this is known) and clear information about how the participation of children and young people will add value. This will ensure children, young people and other stakeholders are fully aware of what their participation involves right from the outset. These need to be documented and used as a reference. This enables everyone involved to have ownership of the project. It is also important that the process is closely audited so that lessons can be learned and the process can evolve and improve. Consideration must also be given to the protection of any data collated (Data Protection Act 1998).

Health and Safety

The health and safety of children, young people and staff must be considered in the planning of a participation initiative. A safe and secure environment is a necessity enabling the process to be accessible by all children and young people whatever their background, experiences, capacities and abilities. There needs to be clear lines of responsibility so that participants know who to approach if there are any difficulties. Alterations and adaptations of the environment may need to be considered as well as resources to aid communication, specific disabilities and requirements. Knowledge of the cultural and ethnic mix of the local population will be useful in planning what resources may be needed. There needs to be a balance between having an environment in which children and young people feel safe and complying with traditional health and safety guidelines in health settings e.g. meeting with young people on the street. Clinicians and Service Leads must take into account their local health and safety guidelines when planning children and young people's participation. It is important that children, young people and their parents/ carers are made aware of the health and safety considerations taken into account.

Confidentiality

Children and Young people have the same basic human right to confidentiality as adults regardless of their age and competence. Should a child or young person disclose information suggesting that they are actually being harmed or are at a significant risk of being harmed then this information needs to be passed on to Children's Services. There should be a clear pathway about the process of breaking confidentiality. In most cases the child or young person involved should be informed of your decision unless it is felt that telling them that you are about to break confidentiality and discuss the information with other agencies will result in the child or young person being at a greater risk of being harmed. There should always be clear documentation of the decisions made and consultations with other agencies.

The rules of confidentiality should be discussed at the beginning of the participation process and clearly displayed in a variety of formats (such as leaflets and posters).

Consent to participate

Consent is the patient's agreement for them to participate in a clearly defined project. It is voluntary and continuing permission needs to be based on an adequate amount of knowledge of the purpose and nature of the project and their role in it. Permission given under undue pressure is NOT consent (Didcock 2006). The ability to give consent is determined by the 'competency' of the child or young person. Competency is influenced by age, cognitive and social development. Emotional factors and family environment can be very influential.

There is no single test of competency in young people, good practice guidelines have jointly drawn up by the BMA and Law Society (BMA & Law Society 2010).

They recommend considering the young person's:

- Ability to understand that there is a choice and that choices have consequences
- Willingness and ability to make a choice (including an option that someone else makes that choice)
- Understanding the nature and purpose of the project
- Understanding the alternatives
- Freedom of pressure

There needs to be a clear policy on the involvement of adults with parental responsibility, whether information needs to be shared with them and whether consent is also needed from a responsible adult. *Guidance for assessing competency in young people (BMA & Law Society 2010)*

Facilitators to note that a briefing on the project and the focus sessions will be communicated with the children and young people prior to the focus sessions and consent forms will be completed and signed by children, young people and parent /carers.

Safeguarding Children and Young People

Safeguarding describes the broader preventative and precautionary approach to planning procedures that need to be in place to protect children and young people from any potential harm. It is imperative that any project involving children and young people is safe and doesn't put them at risk of being harmed or in a vulnerable situation where they feel pressurised to do things that they feel uncomfortable with. On the contrary, a participation activity should increase children and young people's confidence in expressing their views in ways they choose. Section 11 of the Children Act 2004 places a statutory duty on key people and bodies to make arrangements to safeguard and promote the welfare of children. The statutory guidance on the duty, which was first issued in 2005, has been updated. The revised version was published in April 2007.

It requires all agencies to have:

- senior management commitment to the importance of safeguarding and promoting children's welfare;

- a clear statement of the agency's responsibilities towards children, available for all staff;
- a clear line of accountability within the organisation for work on safeguarding and promoting the welfare of children ;
- service development that takes account of the need to safeguard and promote welfare, and is informed, where appropriate, by the views of children and families;
- training on safeguarding and promoting the welfare of children for all staff working with, or in contact with, children and families;
- safe recruitment procedures in place;
- effective inter-agency working to safeguard and promote the welfare of children;
- effective information sharing;
- a local safeguarding policy available to, and accessible by, children and young people.
- The guidance on the duty to cooperate is part of an interlocking set of guidance on the Children Act 2004. (Department for Children, Schools and Families 2006). All adults who have contact with children and young people (depending on the level of contact) may need to have a CRB (Criminal Records Bureau) check either a standard or enhanced check

Facilitators must ensure they are familiar to the local organisations Child Protection Policy and procedures and must have an enhanced CRB check clearance.

Positive Environment

The ethos and culture of the environment is crucial in enabling children and young people to participate. The environment should also be safe, age-appropriate and accessible for children and young people with a range of disabilities.

The Disability Discrimination Act 1995, 2005 requires service providers to make 'reasonable' adjustments for a disabled person to access a service. The active involvement of young people with disabilities is important and to promote disability equality and involve disabled children and young people in participation activities extra resources may be required. Safeguarding procedures enable us to develop a safe and positive environment for children and young people where there is no negligence or unnecessary exposure to avoidable risks.

Where risks need to be taken policies should ensure that they are calculated, carefully managed and communicated to both children, young people, their parents, carers and staff. Involving children and young people will help to promote an environment where their welfare is paramount and should help to develop a culture of inclusion, honesty, openness and mutual respect. It will help children and young people recognise that they have a voice and that their views are important and valued. This will make it more likely that they will feel able to raise any worries or concerns appropriately.

It will be important to be aware of the cultural and ethical diversity of the local population to help all young people to feel safe to take part. Faith and culture can be very important to children and young people' identity and often helps to influence their sense of belonging to any society or can make them feel isolated and different. Lack of awareness may lead to inadvertent prejudicial attitudes and exclude them rather than help bring down barriers enabling equality of access to health services.

Communication

Communication is a two way process between at least two people. Effective communication reassures all parties that they are being heard, their contribution is invaluable, informative and important. Effective communication is central to the meaningful participation of children and young people taking into account their diversity, including age, culture, abilities, disabilities, language, experiences, vulnerabilities, and evolving capacities. Effective communication respects all those involved, it does not esteem one view above another based on status, it assures understanding from a variety of perspectives and takes into account all the expressed views – verbally and non-verbally. Communication can break down for a number of reasons. We must try to anticipate difficulties so that we can fully engage and interact with a diverse range of children and young people.

Equality and Diversity in Participation

“Children and young people’s participation should not reinforce patterns of discrimination and exclusion but seek to address and challenge existing inequalities. Children and young people’s participation should embrace diversity.” Bharti Mepani, RCPCH

Meaningful participation does not seek to categorise children and young people as one homogeneous group and seeks to provide equality for all, regardless of their age, race, colour, gender, language, religion, political opinion, national, ethnic or social origin, disability, or status (or that of their parents/ carers). Recruitment processes must take into account creating opportunities for children and young people with diverse range of experience to participate, including children and young people from marginalised, vulnerable and hard to reach groups.

Participation

- There are different degrees of children and young people’s participation and it is important to be aware of the pitfalls of non-participation such as tokenism, manipulation and decoration.
- The ethos, culture and environment in which children and young people participate should be safe, age-appropriate and accessible for children and young people with a range of abilities.
- Safeguarding children and young people, respecting their confidentiality and ensuring their wellbeing at all times is paramount to the success of any participation initiative and strategy.
- Children and young people’s participation should not reinforce patterns of discrimination and exclusion but seek to address and challenge existing inequalities
- There are many different methods by which children and young people can participate in health services including questionnaires and surveys, focus and

advisory groups, interactive media, youth councils and forums and young researchers.

- Participation has the potential to reduce health inequalities however this requires the involvement of children and young people with a diverse range of experience
- Participation of children, young people and their families in the design and development of services is government health policy.
- The participation of children and young people contributes to the quality of health services for children and young people, it improves the health of children and young people and it's fun!

TERMINOLOGY

Involvement - describes the inclusion of children and young people in some form of decision making process

Consultation - the process by which children and young people are asked for their views and opinions.

Participation - the process by which individuals and/or groups of individuals can influence the decision making process and bring about change

Children and Young People as Researchers

Involving children and young people in research can enhance the quality of the research and provide young people with important skills of planning, information gathering and critical analysis. The safe and meaningful participation of children and young people in research will require researchers to plan the involvement of children and young people to ensure their safety and that their involvement is valued and rewarded. Researchers should build on the research skills that children and young people already possess and ensure that the young people involved in the research reflect the diversity of the population and the range of perspectives.

Focus Session Programme

- ❖ Welcome
- ❖ Introduction
- ❖ Ground rules
- ❖ Focus session outline
- ❖ Focus session purpose
- ❖ Focus session activities
- ❖ Next Steps

Focus Session Method

Focus Groups

Focus groups are a specific form of group interview which incorporate group interaction to explore people's experiences and attitudes. Focus groups were originally used in the media industry to assess audience views and opinions on broadcast media such as film and television. They are now widely used to help understand people's experiences of health services.

The methodology involves the facilitation of group discussion and interaction to allow participants to explore the issues of importance to them. They can help young people clarify their views and thinking in a way that would not be possible in a one-one or group interview. Young people are able to explore the issues relevant to them, in their own language and develop their own priorities and generating their own questions. This can often take participation work in new and unexpected directions.

Focus groups will not be able to gather as much information from as wide a range of participants as a questionnaire however they can provide a much more detailed understanding of the issues and allows the group to explore solutions and answers to problems. They may be inaccessible to some groups and it is important to consider whether the focus group is representative of current or potential service users and which voices may be excluded. Focus groups require a skilful and experienced facilitator in ensuring that young people's participation is safe, confidential and meaningful.

(Extract from Not Just a Phase, RCPCH 2010)

Focus Groups: pros & cons

The facilitator is encouraged to ensure that all participants have an equal opportunity to participate and design/ use methods to facilitate the focus sessions that take into account the evolving capacities of children and young people, whilst dealing with any limitations a focus session may present.

- Accessible to those with literacy problems
- Can encourage those who are reluctant to participate on their own (intimidated by one-one interviews)

- Can encourage participation from those who feel they have nothing to say but will engage with other group members
- Identify shared and common experiences and attitudes as well as breadth of experience and attitudes
- Assist in sharing taboo or stigmatised experiences and attitudes
- Can facilitate the expression of criticism
- May compromise confidentiality
- Not as accessible to young people with verbal communication difficulties
- Group dynamics may silence individual participants
 - Group composition may not be representative

(Extract from Not Just a Phase, RCPCH 2010)

Focus Session Activities

The following activities have been designed to support the effective facilitation of the focus sessions with children and young people between the ages of 6-16 years.

Facilitators are encouraged to adapt the methods, as they see appropriate & within the framework of this guidance, to ensure the meaningful engagement of the children and young people to ensure they have an opportunity to inform the PREM development process. The facilitator will need to discern which activity or combination of activities is most appropriate for the children and young people they will be working with.

Facilitators are also encouraged, where needed, to use additional or alternative methods, bearing in mind the guidance in this pack, including the limitations of the overall project brief. ***If alternative methods are used, the facilitator must describe the method and its analysis as part of the documentation returned to the Project Manager.***

Activity A – What does Urgent & Emergency Care mean?

Activity B – What is important about the U&EC Health Service children and young people receive? Illustrations and experiences

Activity C – Story Box

Activity D – 0-----10 continuum

Activity E – Diamond Ranking

Activity F – Question, Question, Question

Please note, depending on the capacities and abilities of the children and young people the facilitator may vary the combination of the methods used within a session. The **Facilitator must think through the best way to capture the participants input during the focus sessions for all activities without compromising the children and young people's participation.** The amount of time to dedicate to each activity is left to the facilitators' expertise depending on the number of participants, available time, and the number of activities they choose to facilitate/ adapt.

Activity A – What does Urgent & Emergency Care mean?

Aim

- To help us understand what children define as urgent and Emergency Care Services
- To support facilitators explain urgent and emergency care services in the context of this project, taking on board the participants input.
- To manage expectations in relation to the purpose of the focus session and project

Materials

- U&EC Cards
- Blank Cards
- Marker Pens

Process

- Facilitator to ask the participants' to define Urgent & Emergency Care Services, for example 'What do you think Urgent & Emergency Care Services means?'; 'Can you share some examples of Urgent & & Emergency Care Services'.
- Facilitators to write up the participants input onto a flipchart
- Facilitators to note and refer to any input the participants have suggested as Urgent & Emergency Care Services but overlooked so far by the project. These can be written onto the blank cards & referred to throughout the session, where relevant.
- Facilitators to use the participants input plus, if useful the U&EC cards provided (*Institute for Innovation and Improvement*) to further clarify U&EC in the context of this session, reiterate the purpose of the session and the value of their participation.

Activity B – What is important about the U&EC Health Service children and young people receive? Illustrations and experiences

Aim

- To identify areas of importance for children and young people in a U& EC setting
- To understand children and young people's experience of using a U&EC health services

Materials

U&EC Cards

Flipchart

Marker Pens

Process

- Split the participants into groups of three
- Provide each group with a different U&EC Card (if there are more cards than groups provide two –three cards per group).
- Each group to go through the U&EC card and discuss the following:
- Why is this service important for children and young people?
- What is important about the service? Feel free to share examples (speaking, writing, drawing or combination) that help us understand what is important about this service.
- Remind the participants to think through everything that is important from the moment the child or young person accesses the service
- Remind the participants there no right or wrong answers, this is their opportunity to share information that will help us to understand what is important and why
- The groups to come back together and share their U&EC card heading, two points about why it is important and two points that explain what is important for children and young people about that service. Go round each group until all groups have provided feedback. Encourage participants to share items that have not already been shared.
- Provide an opportunity for participants to share any additional points they wish to make in relation to other groups' U&EC Cards.
- Remember participants may share personal experiences to illustrate key points and these should be captured as may reveal additional relevant information.

Activity C– Story Box

Aim

- To identify areas of importance for children and young people in U& EC settings
- Highlight issues from children's perspective about the quality of care they should receive
- To understand children and young people's experience of using a U&EC health service

Materials

Story props, if using them

Process

- In a circle share the main reason why you are here
- Explain that you need their help to create a story
- about a child that visits the GP, then
- uses an ambulance
- that takes him/ her to the hospital
- ...
- Begin to create a story that involves input from the children by asking them questions along the journey of 'story-making'.
- Remember to create space for those children who wish to share personal experiences and what they liked and did not like, what was important to them and what they think would help make things better for the child in the story.
- In the story focus on the child, the journey of accessing health care suddenly and then keep asking the children questions such as: what do you think happened next, why do you think that, how do you think the child is feeling, what would help the child, what else could the Dr do, has anybody ever seen the inside of an ambulance, how do you think the child felt being inside an ambulance.....the child finally arrives at the hospital, how is s/he feeling now....what can s/he see, feel, what do you think s/he is thinking...what would help his/ her time in the hospital.....and so on.
- Keep the questions as open-ended as possible, focussed, simple, and break the story down with questions to ensure as many children who wish to input have the opportunity to do so, encourage their own reflections, and build the story based on their input whilst bearing in mind the overall focus of the focus session. Feel free to use objects or images to help illustrate the journey.

Activity D – 0-----10 continuum

Aim

- To identify areas of importance for children and young people in U& EC settings
- To understand children and young people's experience of using a U&EC health service
- Highlight issues from children's perspective about the quality of care they should receive in a U&EC setting
- To capture the critical questions children and young people would ask other cyp to improve U&EC care

Materials

Flipchart and marker pens

Process

- Building on the feedback from activity B, ask the participants to shout out the key points about what they think is important for children and young people using U&EC services
- Why do they think these items are important?
- Facilitator to ask prompt questions based on the existing evidence. The participants input may support or challenge this evidence.
- List the items on a flipchart, place the flipchart on tables and ask the participants to place an 'x' on a scale of 0-----10 under the relevant items (0 being not great and 10 being really great) based on their experience.
- Ask for volunteers to share why they have placed an 'x' where they have chosen to place it.
- Allow the conversations to flow and continue asking open ended questions to fully understand from the child/ young person's perspective:
 - what is important about the healthcare service/ setting and why;
 - what issues are they concerned about/ have come across;
 - what would help raise the standard of care;

Diamond Ranking

(Possible alternative to the 0—10 activity)

Aim

- To identify areas of importance for children and young people in U& EC settings
- To understand children and young people's experience of using a U&EC health service
- Highlight issues from children's perspective about the quality of care they should receive in a U&EC setting

Materials

Flipchart

Marker pens

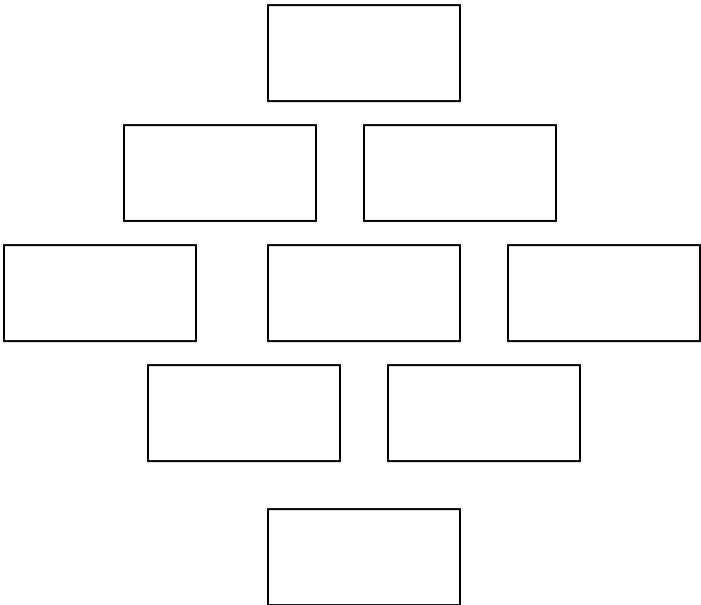
Cards

Process

- Building on the feedback from activity B, ask the participants to shout out the key points about what they think is important for children and young people using U&EC services. Write each item onto a card.
- The Facilitator to ask prompt questions based on the existing evidence and creates further cards, if necessary. Bear in mind the participants input may support or challenge this evidence.
- Participants to 'cluster' the cards that are similar and then diamond rank the cards
- Diamond Rank: Participants to create a diamond with the most important at the top and the least important at the bottom. In order to create the diamond participants need to explore, discuss debate and reach a consensus before deciding where each card fits within the diamond. Participants may end up moving a card several times during this process until a final consensus is reached.
- This is a highly stimulating and interactive way to facilitate discussion and debate, form and express opinions whilst enabling all participants the opportunity to input into the decision making process.
- Facilitators will find it useful to capture the dialogue that takes place as valuable information will be exchanged.
- It will be useful to take a photo of the final diamond rank or draw a copy onto a paper for the report.

Diamond Ranking

Most important



Least important

Question, Question, Question

Aim

- To develop questions for children and young people to improve patient care
- To support the development of the PREM for children and young people.

Materials

Flipchart

Marker pens

Cards

Process

- If we want to find out whether the Urgent and Emergency Care Service children and young people are receiving is of the highest standard: What would your top ten questions be? Think back to everything we have discussed so far and what you think are the key important areas to focus on.
- Facilitators to give the participants time to reflect and explore the areas they think are important to focus on and time to develop questions.
- If necessary, Facilitators to provide prompt questions to support the participants with their thinking.
- Participants to feedback their questions ,use the cards or flipchart to list the questions

Additional information

Given the time constraints it may not be feasible to engage children and young people meaningfully during the analysis but where this is possible, it is advisable the facilitators will liaise with children and young people or representatives from the focus session to analyse the results of the focus sessions.

The RCPCH and the Picker Institute will continue to work with representatives of children and young people from the focus sessions to inform the final report and ongoing development of the PREM.

Documentation

The following data must be provided to the Project Manager, by 25 January 2011:

- Raw Material
- Report
Report on the results and findings, including participants' direct quotes, emerging themes, important areas identified by the participants to support the development of the PREM. Concluding Points, including addressing the Project purpose and the Focus session purpose; Appendix of: Additional methods adopted (if relevant)

The above documentation will support RCPCH and the Picker Institute to:

- Prepare the final report to be presented to the Project Board
- Design the PREM
- Pilot the PREM
- Inform the nationwide implementation of the PREM for Children and Young People to assess and improve their Urgent and Emergency Care Health Service.

Your Role as a Facilitator

In addition to the information already provided in this guide, the following information will assist you further to ensure the meaningful engagement of children and young people in the focus sessions:

- **Respect**
Be respectful to all participants. It is crucial to take seriously and be sensitive to participant's individual differences and perspectives, as well as any discomfort participants may experience in discussing an emotional and personal topic.
- **Judgement**
Be careful in making judgements. Don't reinforce the stereotypes. Keep the focus on the facts.
- **Disclosure**
Please refer to the Child Protection Focal Person for any concerns or referrals on cases or suspicion of child abuse, exploitation and neglect during the focus sessions. Keep all the information related to any incident confidential.
- **Safety and Ground Rules**
Do a quick session on ground rules for the meetings so that participants understand that the meeting environment encourages active participation without judgement; commitment to confidentiality related to personal experiences shared during the focus session; agree to disagree respectfully and generally respect views and opinions of all participants. Know who to contact if there is an emergency, child protection issue, or first aid if required.
- **Ask open-ended questions/ prompt questions**
This is a good way to start and continue a discussion. Open-ended questions start with: How, Why and What ("How does this affect us? Why is it an issue? What can we do to change the situation?"). Open-ended questions provide opportunity for many participants to respond to the same question, refer to personal experience, or expertise.

At times, stand back from group discussions, once the task has been explained to enable participants to explore and discuss freely (so as to ensure they do not look to you to lead the discussion). Use prompt – open ended questions – where this adds value to the activity and facilitates the participants input, exploration, discussion further.
- **Acknowledge different opinions**
When a participant introduces a controversial point, try to separate what is fact from opinion. Should a disagreement occur, encourage participants to challenge the ideas, not the participants.
- **Encourage lively discussions**

Avoid arguments. Facilitate discussions where the focus is on the objectives of the session and consider what is causing the argument and discussing these and talking about strong personal feelings and convictions. Ask challenging questions which will provoke thought. But make sure these are reasonable questions based on what group members know. Ensure that the more 'vocal' do not dominate discussions.

- **Stay focused**

When discussions seem to go off track, try to reintroduce the original issue being discussed (i.e. I think you have a point there, but can we get back to talking about...)

- **Listen**

Listen carefully to what the participants are saying and verify that you heard and understood the information accurately.

- **Responding to Question**

As the facilitator, you will also be asked questions, so you need to prepare how to respond to them. The following could be some of the ways to respond:

- Provide the answer yourself when you are the only person who can do so.
- Redirect the question when there is high probability that the same person or someone else among the participants will be able to come up with the correct answer.
- Defer the question when it is beyond the scope of the group or you need time to find out the correct answer.
- Seek help of a resource person present during the meeting or tell the participants you will get back to them later if you don't know how to appropriately answer the question. Discuss with someone who understands the issue before responding back to participants.

Do

- Position your body so you face all the group members.
- Smile at individuals.
- Listen carefully while they talk.
- Keep eye contact.
- Nod affirmatively.
- Talk with all group members.
- Continually scan the group to make sure everyone is following the discussions.

Don't

- Turn your back to part of the group.
- Frown or look judgmental.
- Don't do anything else like shuffling papers etc. that gives the impression that you are not listening when a participant is talking.
- Avoid eye contact or stare at individuals.

- Remain impassive.
- Talk only to a few people.
- Ask questions that only few can answer & isolate others.
- Ask “trick questions.”

Thank you for supporting to facilitate the U&EC Focus Sessions! Please feel free to contact the Project Manager, should you wish to discuss your brief further to ensure the success of this project. We look forward to receiving your documentation/

All the best!

Bharti Mepani on behalf of the U&EC Project Board

CONTACT DETAILS

U&EC Project Manager: Christine Chow
Royal College of Paediatrics and Child Health
5-11 Theobalds Road
London
WC1X 8SH
Christine.chow@rcpch.ac.uk
020 7 092 6170

PROJECT: TO DEVELOP EVIDENCE BASED URGENT AND EMERGENCY CARE-SPECIFIC PATIENT-REPORTED EXPERIENCE MEASUREMENT (PREM) FOR CHILDREN AND YOUNG PEOPLE TO ASSESS AND IMPROVE THEIR PATIENT CARE.

APPENDIX

Example of the Information Sheet & Consent Form for Participants

Please note the Project Manager will facilitate the completion of consent forms prior to the focus session.



Royal College of Paediatrics and Child Health (RCPCH) Urgent and Emergency Care: School Focus Session

INFORMATION AND CONSENT FORM

Why is the focus session taking place?

The purpose of the focus session is to find out what you think of the urgent or emergency care you have recently received e.g. unplanned GP visits, out-of-hours GPs, Walk-in centres, NHS direct, Ambulance, A&E, etc. We will use the findings to help develop a questionnaire specifically to improve children and young people's experiences of healthcare in the above settings.

Do I have to take part?

Taking part in the focus session is entirely voluntary. It is up to you whether or not you take part. If you are under 16 and you do decide to take part, your parents will need to sign the consent form attached. If you decide to take part, you are still free to withdraw at any time without giving a reason, even on the day.

What will happen if I take part?

Once you have given the completed consent form back to your school you will be invited to attend a focus session with researchers from RCPCH and the Picker Institute Europe on Mon January 17th 2011 at 12pm.

The focus session will take place at your school with the following researchers: Ms Bridget Hopwood (Picker), Ms Amy Tallett (Picker) and Ms Christine Chow (RCPCH). The sessions will last for about 1 hour and will include activities to help you explore your experiences of urgent and emergency care. The sessions will be tape-recorded to help report the findings. There will be a maximum of 6-8 children in each focus session.

What will happen to the results of the focus session?

The recordings will be typed up and analysed. The recordings will be kept for no longer than two months after the focus session takes place. No names will be included in the findings, so nobody will know who said what and everything said within the focus session will be anonymous and confidential. Your contributions in the focus session including drawings and quotes will be used RCPCH reports, publications and promotional material (including print and website) to improve child health.

Who is organising the research?

The research is being organised by RCPCH. We are also working with researchers from the Picker Institute Europe, an independent healthcare research charity with a wealth of patient experience knowledge.

- For more information about RCPCH, please visit <http://www.rcpch.ac.uk>
- For more information about the Picker Institute, please visit www.pickereurope.org

Who do I contact for more information?

If you would like more information about the focus session, please speak to Ms Jennifer Shaw at school.

Thank you in advance. We look forward to hearing about your experiences if you wish to take part in the focus session.

Ms Christine Chow

Project Manager of RCPCH Urgent and Emergency Care Project

Science and Research Department

Royal College of Paediatrics and Child Health

5-11 Theobalds Road,

London WC1X 8SH

Please complete the consent form overleaf and hand it back to your school ASAP.

Please keep the rest of this form for your information.

Title: RCPCH Urgent and Emergency Care: School Focus Sessions

Purpose: To find out what children and young people think of their recent experiences of urgent and/or emergency care

Date: Monday 17th January at 12pm

Venue: The Grey Coat Hospital School (room to be confirmed)

Declaration of consent:

I (Name of Child/Young Person) _____ have read and understood the information attached and agree to take part in the above focus session. I give my consent for RCPCH to use my contributions (including drawings and quotes) from the focus session for RCPCH reports, publications and promotional material (including print and website) to improve child health. I understand that no names will be attached to any findings so my contributions during the session will remain confidential.

Child/Young person signature

Date

Parent/Carer signature
(if you are aged 15 or under)

Date

Please return this completed consent form to your school or else you will not be able to take part in the focus session.

Existing U&EC Evidence Analysis

(Prepared by Christine Chow)

Existing Evidence-based U&EC and/or Paediatric PREM domains

PREM domains

CYP – All healthcare settings:

- Access and Waiting
- Better information about health and healthcare
- Environmental needs in health care
- Building relationships and trusting professionals
- Emotional impact of accessing health care
- Involvement in decisions and control of choices

Source: Better Together - Building on Children's and Young People's Experience (Report No 4/2009), see below for further details.

Paediatric Inpatient and Outpatient setting:

- *Waiting times (and communication re: wait) – (parent)*
- Entertainment while waiting – (child)
- Communication
 - Not explaining what was going to happen
 - Doctor not speaking to child in way could understand
 - Test results
 - Clear answers to questions
 - Medication and side effects
- Child scared or frightened – most often linked to Pain
- Scared of other patients / bothered by noise
- Child involvement in decisions □ didn't always feel 'listened to'
- Privacy when being examined or treated
- *Access to suitable food or drinks (parent facilities)*

Source: Statistically deduced highest scoring problem areas from Picker Paediatric Inpatient and Outpatient Surveys 2010

Paediatric Inpatient setting:

- Food
- Increase activities/facilities for older children
- Further exploration of what is making the children uneasy at night
- Further exploration of the children's access to and awareness of the play area

Source: Improving Patient Care and Experience for Paediatric patients report Nov 2008 (NHS Forth Valley)

U&EC setting – all adults including parents: may or may not be important to CYP

- Confusion over the most appropriate service to use for particular health problems
- 8. Coordination between services
- 9. Informational continuity across services
- Communication
- Ease of access
- Proactive behaviour from health professionals

- Candidacy/real patient involvement

Source: O'Cathain (2008) Characteristics of the emergency and urgent care system important to patients: a qualitative study Note: this study is adult-specific

Better Together: Building on Children's and Young People's Experience – Summary of findings applicable to U&EC PREM focus group

ONE OF THE PRIMARY AIMS WAS TO EXPLORE:

The aspects of health care that is most important to children and young people who use NHS services in Scotland

DEMOGRAPHICS:

- 5 focus groups
- 25 CYP (aged 6-16 years; 17 girls vs 8 boys) with in-patient experience, experience of general practice and/or chronic conditions or disabilities.

FINDINGS - METHODOLOGICAL ISSUES related to this study:

Focus Groups should ideally:

- Be groups of 2-4 especially when working with younger children
- Be formed from natural friendship groups
- Use activities e.g. word showers, picture drawing for 'good' and 'not so good' experiences
- Have two researchers per focus group, especially with younger children
- Include a group with recent (within 6 months) experience
- Finally,
- More in-depth interviews or additional focus groups should be arranged for those with more in extensive/recent experiences

FINDINGS – FOCUS GROUP OUTCOMES:

Six Domains found relevant to CYP (summarised below from Chapter 9: Conclusions, Better Together Report No. 4/2009)

Access and waiting

Age-appropriate things to do
Décor
Long waiting times (=anxiety)

Better information about health and healthcare

- Mixed feelings from CYP as to whether they were able to ask questions about their care – many are happy to rely on their parents
- CYP views on information media were obtained for planned healthcare (i.e. not relevant to U&EC)

Environmental needs in health care

- Physical comfort e.g. beds, waiting room seats, etc (less about cleanliness)

- Food
- Smell (hospital and other healthcare settings, other patients)
- Noise (hospital and other healthcare settings, especially overnight settings)
- Privacy
 - CYP find ill patients disturbing (seeing and being seen by them, especially elderly patients)
 - Young people especially wanted privacy, but also company of other young people – driven by privacy but also want to be apart from young children and old people (extends to drop-in centres so not just hospital setting)
 - Undressing in front of health professionals is a problem (even for children).
- Age appropriate entertainment (mainly from inpatient setting)
- Age appropriate, friendly and non-scary décor (some children found health promotion posters with organs etc quite scary)

Building relationships and trusting professionals

- Young people want to be treated and communicated to in an age-appropriate manner (e.g. not like small children)
- Young children especially want to be seen by friendly (happy) doctors and nurses
- Health professional (e.g. GP, pharmacist) confidentiality is a worry for young people; especially when it comes to seeing the family doctor. None had problems with the family planning clinic because they trusted the clinics to keep their visits confidential.

Emotional impact of accessing health care

- “The overwhelming emotion that came across in the discussions with the children and young people was one of fear and anticipatory fear. This emotion was related to a range of concerns: aspects of treatment, seeing other sick people, being alone, dealing with staff who were not friendly”.

Involvement in decisions and control of choices

- “This did not seem to be major issue in the discussion groups and mixed views were identified. Some children and young people could recount experiences where they really felt listened to and involved and others where things were just done to them with little room for negotiation or explanation. How children and young people would wish to be involved in different aspects of their health care encounters, treatments and hospital stays remains to be further explored”.

Other findings:

- Young people keen to talk about their experiences and keen to use new technologies to access info and make contact with health service providers. There are negative views on using leaflets (boring), websites (unsecure) and enthusiasm for using text messaging (secure/private).

References

- RCPCH, (2010) Not Just a Phase, A Guide to the Participation of Children and Young People in Health Services
- NHS Institute for Innovation and Improvement, (2010) Emergency and Urgent Care – Teachers lesson Plan and Resource Pack
- UK Government, (2010) *Equity and Excellence: Liberating the NHS*. Stationery Office: London.
- Picker Europe (2010) *NHS Surveys: Focused on Patients' Experience*
<http://www.nhssurveys.org/>
- Better Together - Building on Children's and Young People's Experience (Report No 4/2009)
- Department of Health (2008) Better Care: Better Lives Improving Experiences for Children, Young People and their Families living with Life-limiting Conditions
- Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, Tyrer P Systematic Review of Involving Patients in the Planning and Development of Healthcare. *BMJ* 2002;325:1263-1267
- Coad J (2006) Voices of Children and Young People. Involving Children & Young People in the Decision-Making Processes of Healthcare Services, A review of the literature. Action for Sick Children
- Save the Children (2005) Practice Standards in Children and Young People's Participation.
- Save the Children (2004). So you want to consult with children? A toolkit of good practice
- Cooke GA. (2004) Involving Children in Planning Health Care, The Derby Experience. *Current Paediatrics* 2004;14:246-251

Comments and amendments from cognitive tests

Child questionnaire

Question no.	Comment	Action
4	Interviewees 1 and 2 : only waited a short time, it was not necessary for them to be told anything as they knew what was happening – the girl had been before and knew what to expect ie a short wait before being seen. Both ticked 'no' but wanted a 'not necessary' option.	Changed response option 3 to 'No, but this was not needed and added an extra option 'No, but I would have liked to have been told.'
4	Interviewee 4 answered 'yes a bit', and when asked why they explained that they were not initially told but then after some time they were given an x-ray and after this they were kept informed. Therefore they answered in relation to the whole of the waiting experience, as the question intends.	none
4	Interviewee 5 answered 'no but this was not needed' despite ticking 'I had to wait a bit longer than I expected' as he was seen by a triage nurse on arrival, and then had to wait before being seen by the doctor. But he knew why he was waiting and what was happening. He therefore answered question 3 and 4 as the questions intended, considering the overall waiting experience.	none
4	Interviewee 7 ticked 'yes a bit' as he was seen by the nurse and given a nebuliser on arrival at A&E, so knew he was then waiting to see the doctor.	none
5	Interviewee ticked option 4 'can't remember/did not notice' but said she wanted a 'no need/because did not wait' option.	For further testing most people who do not wait should follow the skip at question 3. Interviewee 1 did not follow the skip as he had to wait for a receptionist who was talking on the telephone on entering the A&E department.

Question no.	Comment	Action
5	Interviewee 5 said that he did not really look at the toys etc as he had come prepared for a wait with his Nintendo DS. However, after probing he ticked option 3 'There were things to do but not for me age group.'	Consider an option 'I did not need anything to do.'
5	Interviewee 7 ticked 'yes, there was lots to do' although when probed he admitted that he had been feeling so unwell that he had not really looked, just been aware of books and magazines being around. He commented that when he got to Gloucester hospital Children ward he was given a Nintendo game to play with which took his mind off his asthma and made the time pass quickly.	None
5	Interviewee 9 felt this needed clarifying in the question (ie adding for your age group in the question as well as the response codes). Some respondents commented that they brought their own things to do from home (iPods, Nintendo DS, etc).	Code for 'I had my own things to do' added
6	Interviewees 1 and 2 ticked 'yes mostly' but said that due to their short wait they did not need anything.	Wording of question was simplified to 'could you get everything you needed while you waited?' And an extra response option 'I did not need anything' was added.
6	Interviewee 4 responded 'no' and then when asked if there were no toilets or vending machines available she said that there were but she couldn't physically get to them because she was strapped to a bed.	None
6	Interviewee 5 ticked 'no' but when probed admitted there must have been toilets because his mum used them. He said he ticked 'no' because he would have liked to get snacks from a vending machine but his mum had brought snacks from home!	The wording of the question was changed from 'could you get everything you needed...' to 'was there everything you needed...'
6	Interviewee 7 ticked 'yes mostly' despite the fact that he was too unwell to look around or want snacks, he was aware that facilities were there. He did not spot option 5 which might have been more appropriate.	None

Question no.	Comment	Action
6	Interviewee 11 ticked option 4 'don't know/ can't remember' before seeing option 5 'I did not need anything' which would have been more appropriate for her. She made a general comment that she thought there were too many options to read through.	
7	Interviewee 2 ticked no although she was comfortable, and she didn't need any blankets etc. Interviewee 1 wanted a 'not applicable' box as he didn't need to be kept comfortable.	Changed wording to 'were you looked after while you waited (eg were you given pain medicine, blankets, sick bowls, etc) to simplify and to avoid repeating phrase 'were you able to get everything...' in question 6. Changed option 3 to 'no, I was not' and added new option 4 'no, but I didn't need anything.'
7	Interviewee 5 ticked 'No, but I didn't need anything', although his mum said he had been given Calpol by the triage nurse when he first arrived. The child did not remember this, but chose not to change his answer.	None
7	Interviewee 7's mum reminded him that the nurse had given him a nebuliser when he arrived, he appeared to have forgotten this, perhaps because in distress. He then ticked 'yes definitely' which was appropriate.	None
7	Interviewee 9 was confused as she was given pain relief, but not blankets or sick bowls, so only answered 'yes, sort of'.	This was clarified by putting 'or' in the question.
9	Interviewee 7 ticked 'yes a bit' as he found it all a bit confusing. His mum explained there was some confusion as they seemed to think it was something other than an asthma attack and gave her a sealed envelope to take to Gloucester children's ward which said he had suspected pneumonia. The mother was surprised they hadn't mentioned this to her and felt they were keeping things from her.	
9	Interviewee 8 felt that none of these responses were quite right. She commented that it was 'more than a bit, but not completely - somewhere in between the two'	It was decided 'yes, to some extent' was the best option on the parents' questionnaire, which should then be 'yes, sort of' for children to indicate a middle ground. All questions with the option for 'yes a bit' were changed to 'yes, sort of'.

Question no.	Comment	Action
10	Interviewee 7 ticked 'no' because he felt confused and because of the discussion above. He said he wasn't sure why he was being sent to Gloucester hospital.	As highlighted by interviewee 6, the order of questions 9 and 10 should be swapped as the discussion about what they did comes before their diagnosis.
10	Interviewee 8 pointed out that none of these applied, because while she was in A&E the doctors could not work out what was wrong with her therefore none of these options applied.	An additional code - 'they did not know what was wrong with me' - was added.
11	Interviewee 5 ticked 'yes, completely' despite it being clear that he was not upset or in need of comforting. When probed, he explained that the staff gave him a wheelchair to go to the Xray department, and this was very comfortable. He therefore misunderstood the phrase 'comfort you' in this question.	Review wording of this question perhaps starting with 'if you were upset, do you think...'
11	Interviewee 7 appeared to understand the meaning of this question correctly, as he was upset it possibly had more relevance.	
12	Interviewee 1 and 3 ticked option 2 'yes, a bit' despite describing excellent care. When probed, both said that they chose this option as the doctors/nurses did not actually make them better (both conditions were ones that got better on their own, with time).	Wording changed to: 'do you think that the doctors and nurses did everything they could to help you' in order to reduce focus on getting better/being cured.
12	Interviewee 4 was not sure whether this related to help with getting better, or physically helping them e.g. going to toilet, when in hospital. This was not changed as it can cover both and relates to whether the patient feels they got enough help or not.	
13	Interviewee 1 hesitated over this question finally ticking option 2 'yes, a bit' as he felt a bit nervous that his sore toe was a minor problem and he might be wasting their time.	Changed option 1 to 'yes, completely' to help clarify answers.
13	Interviewee 4 was not sure whether this related to feeling safe with the staff, or feeling that they were polite to them. This was not changed as the question covers both and is subject to the interpretation by the patient as to whether they felt comfortable or not.	

Question no.	Comment	Action
14	Interviewee 8 felt that this was very similar to the previous question – she interpreted ‘comfortable’ to be a ‘safe pair of hands’ so when she reached this one, she was confused as how to answer this. She then talked herself into thinking that Q13 was with the person, and Q14 was the environment, but said that the two were similar. There was also confusion that comfort was referred to twice (in Qs 11 and 13) – this was felt to be misleading.	Q13 was removed as it was harder to distinguish between that and Q11.
15	As with question 12, both interviewees 1 and 2 ticked option 2 despite having exemplary care, they did not leave A&E pain free and the staff did not make the pain go away.	Changed wording to ‘if you were in pain, do you think the staff did everything they could to help with your pain?’ to remove reference to pain ‘going away’
16	Interviewee 1 and 2 were examined in an open plan space and both felt that the nature of their conditions meant that they didn’t need somewhere private.	The ‘no’ option was split into ‘no, but I did not need this’ and ‘no, but I would have liked this’.
17	Interviewee 4 felt that they did not fall into any of the response options, and explained that they received ‘some but not enough information’ but that the response ‘a bit’ did not make sense in the context of this question.	Response options altered from ‘yes definitely’, ‘yes, a bit’ and ‘no’ to ‘enough information’, ‘some, but not enough information’ and ‘no information at all’
17	Interviewee 7 answered ‘yes, definitely’ after consultation with his mum. His mum said he wasn’t really aware of the information she was given.	Consider simplifying the wording by replacing ‘receive’ with ‘get.’
17	Interviewee 8 answered ‘they did not know what was wrong with me’; this was added.	
18	Interviewee 8 commented that none of these were relevant as she was admitted to hospital after her A & E visit and this assumes that people went home afterwards.	A ‘filter’ question was inserted before the aftercare section to establish the route they took after their urgent care episode. Those who were admitted to hospital (‘I stayed overnight in hospital’) were routed past the aftercare section to Q21
18	Interviewee 11 had to read this question several times and said the phrase ‘watch out for at home’ was rather odd, she finally ticked option 5 ‘don’t know’ rather than ‘this was not needed’ which would have been more appropriate in her case.	

Question no.	Comment	Action
19	Interviewee 1 hesitated over this question and finally ticked option 5 as he wasn't sure if info about danger signals was needed. Option 4 would have been more appropriate but it was difficult for him to make a judgement. Interviewee 5 hesitated over this question, finally correctly ticking option 4 'this was not needed.' When probed he said he thought it would get better on its own and was not going to get worse, but as he was going on a school trip the next day advice on what to do if things got worse might have been helpful.	Agreed to review after further cognitive testing.
19	Interviewee 7 was prompted by his mum that they had been given advice on how to use the nebuliser to prevent another asthma attack. The child then ticked 'yes a bit' but could not really remember what he was told, and he did not associate this with the phrase 'danger signals', as his mum explained, with asthma it is a matter of prevention (asthma symptoms are themselves the danger signals).	Possibly review use of the phrase 'danger signals'?
20	Interviewee 7's mum was clear that they had been given this information, so the child ticked 'Yes' although he could not remember this himself. Mum said that parents would naturally deal with the paperwork and the child would not necessarily know what she had been given.	
20	Interviewee 11 said she would have liked another option here for 'was not needed.'	
21	Interviewee 8 felt this was a little 'complicated' and could be simplified.	Wording changed to: 'was the main reason that you came here dealt with well?'
21	Interviewee 11 had to read this question twice, but then understood it.	
25	Interviewee 4 recognised that the word 'child's' should not be in the sentence.	The word 'child's' was removed from the question because it hadn't been altered from the version on the parent's questionnaire.
25	Interviewee 7 checked with his mum before ticking the 'white' box although there was no doubt he was white he had clearly not filled in an ethnic background question before – he also asked what the word 'ethnic' meant.	

Response profile for all questions used

Please note:

E – Emergency department version

A – Ambulance version

G – GP version

*where included are to indicate the response options that have been used in the problem score calculation

E1. If an ambulance was called, did the ambulance staff/paramedics explain what was happening in a way you could understand?

All patients (Emergency Dept Survey only)	%
Yes, definitely	5.5%
Yes, to some extent / sort of	1.8%
No	0.9%
An ambulance was not called	55.8%
I can't remember	0.5%
Not answered	35.5%

E1+. If an ambulance was called, did the ambulance staff/paramedics explain what was happening in a way you could understand?

All patients (Emergency Dept Survey only)	%
Yes, definitely	12.5%
*Yes, to some extent / sort of	4.2%
*No	2.1%
I can't remember	1.0%
Not answered	80.2%
Problem score	6.3%

E2. Overall, how well do you think ambulance staff/paramedics looked after you/your child?

Those who called an ambulance (Emergency Dept Survey only)	%
Very well	13.5%
Fairly well	4.2%
*Not very well	0.0%
*Not at all well	0.0%
I can't remember	1.0%
Not answered	83.3%
Problem score	0.0%

E3/G1/A1. How did you feel about how long you had to wait to be seen?

All patients	%
I/we did not have to wait at all	23.1%
The wait was shorter than expected	40.2%
The wait was about as long as expected	18.3%
The wait was longer than expected	10.5%
Not answered	7.9%

E3+/G1+/A1+. How did you feel about how long you had to wait to be seen?

Those who waited	%
The wait was shorter than expected	52.3%
The wait was about as long as expected	23.9%
*The wait was longer than expected	13.6%
Not answered	10.2%
Problem score	13.6%

E4/G2/A2. While you were waiting, did someone tell you/keep you informed about what was happening?

Those who waited	%
Yes, definitely	29.0%
Yes, to some extent/sort of	11.9%
No, but this was not necessary/needed	42.6%
* No, but I/we would have liked to have been told	9.7%
Don't know/can't remember	2.3%
Not answered	4.5%
Problem score	9.7%

A3. While you were waiting, did someone tell you what to do?

(Interpret with caution – low number of respondents.)

Those who waited (Ambulance Survey only)	%
Yes, definitely	42.9%
Yes, to some extent/sort of	28.6%
No, but this was not needed	14.3%
*No, but I/we would have liked to have been told	14.3%
I can't remember	14.3%
Not answered	0.0%
Problem score	14.3%

E5/G3. Was there enough for you/your child to do when waiting to be seen (such as toys, games and books)?

Those who waited (Emergency and GP survey only)	%
Yes, lots to do	18.3%
*Yes, some things, but not enough	10.7%
*There were things, but not for my/my child's age group	18.9%
*No	33.1%
Can't remember/did not notice	5.3%
We had our own things to do to	9.5%
Not answered	4.1%
Problem score	62.7%

E6/G4. Was there everything you needed while you waited (such as food, drink and toilets)?

Those who waited (Emergency and GP survey only)	%
Yes, definitely	32.0%
*Yes, to some extent/sort of	33.7%
*No	10.7%
We did not need anything	20.1%
Don't know/can't remember	0.6%
Not answered	44.4%
Problem score	10.7%

E7/G5. Were you/your child looked after while you waited (for example, given pain medicine, blankets or sick bowls if needed)?

Those who waited (Emergency and GP survey only)	%
Yes, definitely	25.4%
*Yes, to some extent/sort of	5.3%
*No	5.9%
We did not need anything	56.2%
Don't know/can't remember	1.2%
Not answered	5.9%
Problem score	11.2%

E8/G6. How clean was the waiting area?

Those who waited (Emergency and GP survey only)	%
Very clean	43.8%
Quite clean	43.8%
*Not very clean	9.5%
*Not at all clean	0.0%
Can't remember/did not notice	0.6%
Not answered	2.4%
Problem score	9.5%

E9/G7/A4. Did staff explain what they were doing in a way you could understand?

All patients	%
Yes, completely	71.6%
*Yes, to some extent/sort of	17.5%
*No	1.3%
I did not need an explanation	4.8%
Don't know/can't remember	0.9%
Not answered	18.8%
Problem score	1.3%

E10/G8/A5. Did staff explain what was wrong with you/your child in a way you could understand?

All patients	%
Yes, completely	66.8%
*Yes, to some extent/sort of	21.0%
*No	2.6%
Don't know/can't remember	1.3%
They did not know what was wrong with me/my child	1.7%
Not answered	6.6%
Problem score	23.6%

E11/G9/A6. Did staff do everything they could to calm and comfort you/you and your child?

All patients	%
Yes, completely	64.2%
*Yes, to some extent/sort of	16.2%
*No	1.7%
This was not necessary/needed	13.5%
Not answered	4.4%
Problem score	17.9%

E12/G10/A7. Did you/your child feel safe/at ease with the staff they saw?

All patients	%
Yes, completely	76.4%
*Yes, to some extent/sort of	16.2%
*No	0.9%
Not answered	16.6%
Problem score	17.0%

E13/G11/A8. If you/your child was in any pain, did staff do everything they could to help with your pain?

All patients	%
Yes, definitely	48.9%
Yes, to some extent/sort of	14.8%
No	1.7%
I/my child was not in any pain	28.8%
Not answered	5.7%

E13+/G11+/A8+. If you/your child was in any pain, did staff do everything they could to help with your pain?

Those who were in pain	%
Yes, definitely	68.7%
*Yes, to some extent/sort of	20.9%
*No	2.4%
Not answered	8.0%
Problem score	23.3%

E14/G12. Were you/your child given enough privacy when being treated and examined?

All patients (Emergency and GP survey only)	%
Yes, definitely	80.5%
*Yes, to some extent/sort of	6.3%
*No, but I/we did not mind	3.6%
*No, but I/we would have liked this	0.0%
Don't know/can't remember	2.3%
Not answered	7.2%
Problem score	10.0%

E15/G13/A9. During your care did you receive enough information about your/your child's condition and treatment?

All patients	%
Yes, completely	76.4%
*Yes, to some extent/sort of	16.2%
*No	0.9%
Not answered	16.6%
Problem score	17.0%

E13/G11/A8. If you/your child was in any pain, did staff do everything they could to help with your pain?

All patients	%
Yes, enough information	75.1%
*Some, but not enough information	7.0%
*None, but I would have liked some	1.7%
None, but I did not need any	7.0%
They did not know what was wrong with me/my child	0.9%
Not answered	8.3%
Problem score	8.7%

E16/G14/A10. Do you think staff did everything they could to help you/your child?

All patients	%
Yes, definitely	79.0%
*Yes, to some extent/sort of	11.8%
*No	1.3%
Don't know/can't remember	0.9%
Not answered	7.0%
Problem score	13.1%

E17/G15/A11. After your emergency visit/care, what happened?

All patients	%
Went to hospital/stayed overnight in hospital	6.6%
Went home/stayed at home	1.3%
Other/went to stay somewhere else	17.5%
Not answered	74.7%

E18/G16. Did someone tell you when you/your child could re-start your/their usual activities, such as playing sport and returning to school?

Those who did not stay in hospital (Emergency and GP survey only)	%
Yes, definitely	36.8%
*Yes, to some extent/sort of	8.0%
*No	7.5%
This was not needed	32.1%
Not answered	15.6%
Problem score	15.6%

E19/G17/A12. Did someone tell you what you should watch out for at home after your/your child's emergency care?

Those who did not stay in hospital	%
Yes, definitely	45.8%
*Yes, to some extent/sort of	11.2%
*No	5.6%
This was not necessary/needed	20.6%
Don't know/can't remember	0.9%
Not answered	16.8%
Problem score	15.9%

E20/G18/A13. Did staff tell you what to do or who to contact if you were worried about anything after the emergency care?

Those who did not stay in hospital	%
Yes	70.1%
*No	10.3%
Don't know/can't remember	4.7%
Not answered	15.0%
Problem score	10.3%

E21/G19/A14. Overall, how well do you think you/your child was looked after?

All patients	%
Very well	69.0%
Fairly well	20.5%
*Not very well	1.3%
*Not at all well	1.7%
Not answered	8.7%
Problem score	2.3%

E22/G20/A15. Was the main reason for your emergency visit/care dealt with well?

All patients	%
Yes, completely	71.2%
*Yes, to some extent/sort of	15.7%
*No	0.4%
Don't know/can't remember	0.4%
Not answered	12.2%
Problem score	16.2%

E23/G21/A16. Who was the main person who answered the questions on this survey?

All patients	%
Child (patient)	17.9%
Parent/carer	59.4%
Both child and parent/carer together	14.0%
Not answered	8.7%

E24/G22/A17. Are you/is your child male or female?

All patients	%
Male	43.7%
Female	50.7%
Not answered	5.7%

E25/G23/A18. How old are you/is your child?

All patients	%
0-2 years old	21.8%
3-5 years old	13.1%
6-8 years old	13.1%
9-11 years old	14.8%
12-14 years old	3.9%
15-16 years old	9.6%
Not answered	11.4%
Invalid*	12.2%

* Invalid age is when the age appeared to be of the parent/carer instead of the child – as the age was over 16 years. Since it is the child's age we are interested in, the parent age has been deleted. This is likely to have occurred because in some instances, parents of younger children aged 0-7 years were incorrectly handed the children's version of the questionnaire instead of the parent version. The children's questionnaire was worded for children, therefore the age question read 'How old are you?' rather than 'How old is your child?'. Where the parent answered, they have put their own age instead of their child's age, which is what we wished to capture.

E26/G24/A19. Which of these best describes your/your child's ethnic background?

All patients	%
White (eg British, Irish, European)	67.2%
Mixed (eg White and Asian)	4.8%
Asian/Asian British (eg Indian)	9.6%
Black/Black British	7.0%
Chinese	0.4%
Any other ethnic group	2.6%
Not answered	8.3%

E27/G25/A20. Which of these is the MAIN language spoken at home?

All patients	%
English	79.5%
Other European language	10.0%
Asian language (such as Hindi, Gujarati, Punjabi, Urdu, Bengali, Thai)	3.9%
African language (such as Swahili, Hausa, Yoruba)	0.9%
Other, including British Sign Language	2.6%
Not answered	3.1%

Problem scoring statistics for emergency department version

	N	Mean	Standard deviation	Skew	Standard error
E3P	151	0.14	0.35	2.07	0.03
E4P	161	0.10	0.30	2.65	0.02
E5P	162	0.65	0.48	-0.64	0.04
E6P	164	0.46	0.50	0.17	0.04
E7P	159	0.12	0.33	2.32	0.03
E8P	165	0.10	0.30	2.70	0.02
E9P	208	0.21	0.41	1.44	0.03
E10P	202	0.25	0.44	1.13	0.03
E11P	207	0.18	0.38	1.66	0.03
E12P	203	0.18	0.39	1.63	0.03
E13P	140	0.25	0.43	1.14	0.04
E14P	201	0.10	0.31	2.57	0.02
E15P	198	0.10	0.30	2.63	0.02
E16P	201	0.15	0.36	1.95	0.03
E18P	176	0.19	0.39	1.59	0.03
E19P	176	0.20	0.40	1.50	0.03
E20P	178	0.12	0.32	2.35	0.02
E21P	198	0.02	0.14	6.77	0.01
E22P	189	0.19	0.39	1.56	0.03



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).