Recommending a Friends and Family Test (FFT) for Children and Young People

February 2015

Health Experiences Team, Picker Institute Europe
Picker Institute Europe

Picker Institute Europe is an international charity dedicated to ensuring a positive experience of health and social care is everyone’s experience. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people’s needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people’s feedback.

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Executive Summary

Background

Ahead of it becoming compulsory for the Friends and Family Test (FFT) to be asked to patients aged under 16 years old in April 2015, Picker Institute Europe explored children’s views of the FFT question to recommend a version that is suitable for a younger patient population. This was conducted in collaboration with Barts Health NHS Trust and achieved by following the stages:

1. **Focus Group**
   - A focus group with young patients at the Royal London Hospital explored views of hospital care in general, in addition to the FFT question and different ways it could be asked. This informed the development of four versions of the FFT question, presented alongside a variety of images and using a range of designs. Views on wording and presentations were sought during short ward interviews, from which the preferred version was selected. This was developed into a full FFT form before being cognitively tested with a new set of patients to check for comprehension and overall format.

2. **Pilot**

Methods

A focus group with young patients at the Royal London Hospital explored views of hospital care in general, in addition to the FFT question and different ways it could be asked. This informed the development of four versions of the FFT question, presented alongside a variety of images and using a range of designs. Views on wording and presentations were sought during short ward interviews, from which the preferred version was selected. This was developed into a full FFT form before being cognitively tested with a new set of patients to check for comprehension and overall format. A pilot of the data collection phase was then conducted across two NHS Trusts: Barts Health NHS Trust (the Royal London Hospital site) and University Hospital Southampton NHS Foundation Trust (Southampton Children’s Hospital). Each site selected three paediatric inpatient and day case wards to participate.

Results

Children’s views (ages 7-16 years) on the FFT question and wording can be summarised as follows:

- **Question text** – the phrase ‘if they needed similar care or treatment to me’ is essential to children’s understanding of the question. The words ‘suggest’ or ‘recommend’ are not always understood.

- **Response options** – there was a preference for fewer response options from the younger children (under 10 years) only. However more response options ensured that a broader range of responses was used. With fewer response options, many selected the top option only. The ‘likely’ and ‘unlikely’ response options were not understood by all. An ‘agree’ to ‘disagree’ scale was more favoured. ‘I can’t decide’ and ‘don’t know’ were deemed too similar and indistinguishable.
• **Images** – images of Monkey in hospital were favoured over cartoon animations which were deemed more suitable for younger children, and also compared to easy-read photos that were felt to be unrealistic.

• **Scale images** – a Monkey face picture scale was initially well received, however there were some problems in what the different images represented. The colourful smiley faces were favoured and less ambiguous.

The recommended FFT question for children and young people was as follows, and designed based on children’s preferences:

I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me.

Please tick one only.

☐ I agree a lot
☐ I agree a bit
☐ I disagree a bit
☐ I disagree a lot
☐ I can’t decide/ I don’t know

The question was incorporated onto a two-sided A4 survey form alongside freetext follow-up questions, date of hospital attendance, and demographic questions. It was then piloted across the two hospital sites using a hand-out paper methodology with an additional online option for children to complete using their smartphones, computers or tablet devices.

A total of 672 completed forms were returned during the six-week fieldwork period – 307 from the Royal London Hospital and 365 at Southampton Children’s Hospital. The majority of respondents either ‘agreed a lot’ (90%; n=600) or ‘agreed a bit’ (8%; n=51) that the hospital was a good place for their friends and family. There were minimal differences in responses to the FFT question by demographic group (gender or age) – however, significance testing was not conducted to identify statistical differences. Approximately two thirds of respondents left freetext comments. These were from both parents and young patients and provided constructive feedback in terms of positive feedback in addition to areas for improvement in paediatric care provision.

**Conclusions**

It is essential to involve young patients in the development and design of any new survey to ensure it is appropriate and appeals to their needs, abilities, and preferences. Without thorough testing and exploring how young people understand and respond to questions, we cannot guarantee the validity of survey responses. The pilot demonstrated ceiling effects whereby the

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1 https://www.monkeywellbeing.com/
majority of responses to the children’s FFT question were positive, with poor discrimination between demographic groups. However, constructive feedback was provided in the form of freetext comments.

Picker Institute Europe would make the following recommendations to NHS England regarding implementation of the FFT for children and young people:

(i) **FFT question**: the adult version of the FFT should not be used with children and young people. Instead, we would promote use of our child-friendly recommended question as the default for this patient population.

(ii) **FFT score calculation**: the new reporting scores from October 2014 requires combining the percent of people responding ‘agree a lot’ and ‘agree a bit’. This would be 98% of patients for the pilot data, which hinders the ability to distinguish between good and poor hospital experience. It is therefore essential to report on individual categories to capture the percentages responding to each of the response options individually (agree a lot, agree a bit, disagree a bit, disagree a lot). However, even this approach would not guarantee the usefulness of the quantitative data given the strong ceiling effects that were observed.

(iii) **Freetext comments**: As in adult settings, patient and carer comments were found to be informative and useful. Freetext comments should therefore be sought from as many children as possible, in line with national guidance.

Picker Institute Europe are now researching recommended wording for children’s GP, community and ambulance FFT questions, in addition to looking into a version suitable for patients with a learning disability.
Background

The Friends and Family Test (FFT) initiative aims to provide real time feedback by measuring patient experience across a variety of healthcare settings. The FFT is currently in use nationally in adult acute care settings including inpatient wards, emergency departments, and maternity services, and more recently in mental health, community health and GP settings. Following the revised ‘making the FFT inclusive’ part of the guidance published in July 2014\(^2\), it will be compulsory for children and young people to be offered the FFT question across all care settings from 1\(^{st}\) April 2015.

The guidance requests that children and their families should initially be asked the adult version but with the option to use supplementary information or a child-friendly alternative should they fail to understand the original wording. Picker Institute Europe had a number of concerns with the methodology for children and young people.

Firstly, the adult version of the question may not be fully understood by children and young people, particularly since adults have shown difficulty in responding to questions about making recommendations about their hospital care to others (Graham & MacCormick, 2012\(^3\); Picker Institute Europe, 2014\(^4\)). Although the revised FFT guidance released in July 2014 incorporates a recommended question wording and various example designs for children and young people, there is no development report or evidence to suggest that the wording and presentation of the questions have been tested with children and young people.

Secondly, it is logistically more difficult and time consuming to implement and report the FFT if there are multiple versions of the question across paediatric care settings. This would require children being asked the FFT in an interview setting by staff, who would then need to make an accurate judgement on a child’s understanding of the question to decide whether or not to give them an alternative wording.

Finally, although the guidance recommends a question that may be used with children and young people, there is flexibility around the exact question text and response options that can be used, in addition to the methodology and timing. A compulsory question that has been thoroughly tested with children would ensure that they understand the question and in turn maximise the validity of the data that it yields.

Picker Institute Europe, in collaboration with Barts Health NHS Trust, therefore embarked upon a project to address children’s views of the FFT question and explore their preferences in:

- Question text wording
- Response options – text and number of options
- Images and presentation style

\(^3\) [http://www.nhssurveys.org/Filestore/reports/Overarching_questions_for_patient_surveys_v3.pdf](http://www.nhssurveys.org/Filestore/reports/Overarching_questions_for_patient_surveys_v3.pdf)
The overall aim was to recommend an FFT question that is suitable for a younger patient population in advance of the FFT for children and young people becoming mandatory in April 2015.

Methods

A friends and family test question for children and young people was recommended after completing the stages outlined in Figure 1.

Figure 1: Methodological Stages

Stage 1: Focus Group Discussion

In June 2014, a focus group was held at the Royal London Hospital with young patients to explore views on patient feedback and on different versions of the FFT, including wording and presentation. Young patients were asked about recent experiences of care and also consulted on survey implementation methods appropriate for reaching a younger audience. The adult version of the FFT in addition to existing children’s versions were shared during the group to explore their views.

Children aged 8-16 years old were eligible to take part in the group if they had been admitted to Barts Health NHS Trust as an inpatient or day case patient within the last three months. The group was facilitated by two staff members from the Picker Institute, and it lasted approximately one hour. Some patients were pre-recruited via posting and handing information out to recent patients, whereas others were recruited on the day (current inpatients – ensuring only those who were well enough were invited to participate). All opted in to participate. Parents of children aged under 16 were required to give consent on behalf of their children, whilst 16 year olds were able to give consent themselves. All participants were given a £20 gift voucher to thank them for their time.

Stage 2: Question Development

Findings from the focus group discussion were used to inform the development of various examples of the FFT question, varying in language and design, based on children’s wording and presentation preferences.

Stage 3: Ward Interviews

A series of draft FFT questions were presented to children during ward interviews, to obtain their individual views outside of a group setting. The interviews were conducted by Picker Institute Europe staff, and took place across wards 7E and 7F at the Royal London Hospital. These wards were selected due to the high numbers of inpatients staying on the wards. Each interview lasted
only 15-20 minutes, as it was not felt that longer interviews were suitable for patients who are currently in hospital.

Participants were recruited on the day – a ward manager identified those who were well enough and able to participate. They were recruited by a member of staff, usually a nurse, who let them know that researchers were on the ward or clinic to talk to young patients about methods of gathering their feedback. If they were interested in taking part, they were given an information sheet and a consent form. All participants were under 16, so parental consent to take part was obtained. In most cases a parent was also present during the interview, but feedback was provided by the child or young person, not the parent. Each participant was given a £10 shopping voucher to thank them for their time.

During the ward interviews, participants were consulted on their views on four draft FFT questions, each presented with different wording, scales and image options. The order of presentation was rotated to counterbalance for order effects. Participants were asked to read each question out loud to ensure that they could read the question. They were then asked various questions and probed to assess the following:

- Could children understand the question? What was their interpretation/ what did they think the question meant, and was it appropriate?
- Were there any words that were difficult to read or understand?
- Could children read and understand the response options, were they relevant, and was it easy to choose one?
- Were the scale images helpful in deciding which response option to choose?
- Which version was preferred in terms of the language used, images, and scales?

Findings were used to design an FFT form for children and young people, which included demographic questions (age and gender), the preferred FFT question and follow-up freetext questions.

Stage 4: Cognitive Testing

A children’s FFT survey form was professionally designed based on feedback from the focus group and ward interviews in terms of the preferences of young patients (please refer to Appendix 1). It was then cognitively tested with a new group of young patients. Cognitive testing is an important stage for any new survey tool. It involves going through the questionnaire with members of the target group to ensure that the survey questions are appropriate and relevant, to maximise the validity of the data that is collated.

Participants were presented with the form (see Appendix 1), and probed into what they thought the questions mean (with a particular focus on the FFT question) and why they chose the answer they provided. It allows for an understanding of:

- Comprehension – is the wording relevant? Do children and young people understand what is being asked? Is the question interpreted correctly?
- Recall – is the participant able to accurately recall the information required to answer the question?
Appropriateness of the available response options – is the participant able to answer using the available response options? Do they understand the meaning of each response option? Overall design – what are children’s views of the form design and layout?

On the spot recruitment of current inpatients was conducted at the Royal London Hospital, with patients being approached by researchers in busy paediatric wards under supervision of a ward manager.

Parental consent was obtained for all participants, and each participant was offered a £10 shopping voucher. The cognitive tests were approximately 10 minutes in length.

Stage 5: Pilot

The children’s FFT form was amended slightly according to the cognitive interview findings prior to being piloted. Two pilot sites were selected, Barts Health NHS Trust and University Hospitals Southampton NHS Trust, to trial full implementation, data collection and analysis of the survey results. A paper methodology alongside an online version of the FFT form was deemed most suitable for data collection, since it is logistically easier and more cost effective to use paper forms on busy paediatric wards. The online option allowed young people to respond using their smartphones, laptops, or tablet devices.

Surveys were printed by Picker Institute Europe and posted to participating wards. All forms were pre-coded with the ward name. Ward staff were instructed to hand out forms to all patients under 18 on their wards, ideally as they were approaching discharge. Staff were provided with an instruction sheet for disseminating the forms. Forms were handed out from October 2014 for a period of 6 weeks to trial data collection. A copy of the form that was piloted is located in Appendix 2.

Participating wards were as follows:

Barts Health NHS Trust (all based at the Royal London Hospital site):

- 6B – day ward
- 7F – inpatient
- 7E/C PASSU – short stay inpatient

University Hospital Southampton NHS Foundation Trust (all located within Southampton Children’s Hospital):

- E1 – inpatient
- G3 – inpatient
- John Atwell (JA) – day ward

Patients returned their completed forms to a drop box placed visibly on the ward. Each ward then posted the completed forms back to the Picker Institute on a weekly basis for data entry. Standard quality checks were in place, and all data was thoroughly checked and cleaned prior to analysis. This included removal of any patient identifiable information such as patient or staff names in the freetext boxes.
Results

Results from each stage are presented in the following subsections. Some quotes from patients during the qualitative stages are included in purple italics.

Stage 1: Focus Group Discussion

A total of 8 patients aged between nine and 16 years old took part in the focus group. Table 1 indicates their age, gender and reason for admission to hospital.

Table 1: Focus group participants

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Reason for hospital admission</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>9</td>
<td>Male</td>
<td>Sickle cell disease</td>
</tr>
<tr>
<td>2</td>
<td>9</td>
<td>Male</td>
<td>Sickle cell disease</td>
</tr>
<tr>
<td>3</td>
<td>16</td>
<td>Female</td>
<td>Digestive long-term condition</td>
</tr>
<tr>
<td>4</td>
<td>16</td>
<td>Male</td>
<td>Cystic fibrosis</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>Female</td>
<td>Cystic fibrosis</td>
</tr>
<tr>
<td>6</td>
<td>15</td>
<td>Female</td>
<td>Involved in car accident</td>
</tr>
<tr>
<td>7</td>
<td>10</td>
<td>Female</td>
<td>Involved in car accident</td>
</tr>
<tr>
<td>8</td>
<td>12</td>
<td>Female</td>
<td>Diabetes</td>
</tr>
</tbody>
</table>

Most of the young participants were very familiar with the hospital, either as a result of the length of their current hospital stay, or having to return to the hospital regularly for their chronic condition. They discussed the day-to-day running of the hospital and could explain what worked well and what could be improved, with comments ranging from communication between staff and patients to the available play facilities.

Implementation preferences

Children were asked for their opinions on different feedback methods and whether they had seen or used these in the past. Pictures and examples were presented to young patients during the group. Methods included:

- Postcard – A5 paper survey form to complete and hand back to the hospital
- Paper survey – A4 paper survey form with pictures and colour
- Kiosk / bedside TV – A survey loaded onto a touchscreen kiosk or bedside TV
- Tablet device – A touchscreen device handed to by a member of staff to complete in hospital

The postcard was seen as the least popular method as the young patients felt there was not enough space to write in the boxes. This was especially important for the younger patients and those with large handwriting. The size of the postcard left no room for images resulting in the young people describing the form as boring and dull. Therefore any paper option should be large enough for children to write their comments, and space for including pictures to make the form appealing.
“I don’t think that [the postcard] would be very appealing, there’s too much writing and... there’s not enough space to write, you need more space.”

The kiosk/bedside TV was not overly popular with young patients since many had experienced problems with equipment failure, and also having to sit in uncomfortable positions to see the screen. Furthermore, this method was often difficult for patients that needed to be attached to medical equipment. Additionally, not all wards had bedside TV facilities.

“The nurses said [the bedside TV] should work and it just didn’t, after two minutes it just didn’t work....”

Tablet devices were considered a fun way of providing feedback, however not all hospitals or wards have access to tablets and software required to run the survey on these devices.

Image preferences

During the focus group, various images were introduced to young patients to determine their views – see figure 2. Set 1 (animations) and 2 (photos) were from existing Picker children’s surveys and ‘easy read’ surveys (for adults with learning disabilities). A set of Monkey images were also presented to children, as these images were being used in other hospital information documents for children.

Figure 2: Images tested in focus group

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5 [www.monkeywellbeing.com](http://www.monkeywellbeing.com)
Set 1, the Picker children’s survey animations, were generally felt to be more applicable for a younger audience only. Older children found them less appealing and felt patronised by these:

“...a bit patronising, they’re not as cute as the monkeys.”

“Only for young ‘uns but personally I think the pictures are a bit annoying.”

The easy read survey animations (set 2) were deemed unrealistic, with participants stating the hospital looks too clean and the people are too happy to be in hospital:

“Bit too much of a brochure.”

“It looks like an American TV show. You’d probably look at it and think, well how come everything’s so bright.”

“Too happy!”

Monkey images (set 3) were preferred by most, exciting patients who asked lots of questions and tried to name the monkey. The patients, both younger and older, engaged with the monkey character:

“I like the monkey.”

“Who doesn’t like monkeys! Everyone likes monkeys.”

“He’s so cute!”

Participants were also shown different image scales alongside response options to aid their interpretation of the question – please refer to figure 3.

The ‘Monkey’ picture scale was initially appealing, but after exploring further, various problems were revealed in terms of what the different images represented. The first four pictures were perceived to be a scale that could correspond to experience, whereas the final two pictures were described with words such as angry, shocked, confused and outraged. It was felt that some CYP would avoid these response options even if their experience was poor, as a result of the unappealing picture alongside.

Figure 3: Scale images tested in focus group
The smiley faces were well received and less ambiguous than the Monkey scale. They were felt to be a good way of expressing feelings, and most gave positive feedback about these images. Children preferred the colourful traffic-light coded smileys to the black and white smiley face scale, finding them more appealing and meaningful.

“I think that [the smiley faces] would need a colour though because just looking at the top one [black and white smileys] is hard to look at.”

“I suppose the smileys could be used to sum up your overall experience or you could independently use them for each specific thing.”

**Question wording preferences**

Participants were presented with various versions of the question wording (see figure 4), including the adult FFT (see example 4), and the version recommended for children and young people in the guidance and at Birmingham Children’s Hospital (see example 1). They were probed on their views and how they interpreted the question.

**Figure 4: Question wording tested in focus group**

**QUESTION EXAMPLE 1:**

I would say this is a good hospital for my friends & family to be looked after in, if they needed similar treatment or care to me.

- I agree a lot
- I agree a bit
- I am undecided
- I disagree a bit
- I disagree a lot
- I don’t know

**QUESTION EXAMPLE 2:**

Is this a good hospital for your friends & family to go to, if they needed to go to hospital?

- Yes, definitely
- Sort of
- No
- Don’t know

**QUESTION EXAMPLE 3:**

If your friends and family needed to go to hospital, would you suggest this hospital to them?

- Yes, definitely
- Probably
- No
- Don’t know

**QUESTION EXAMPLE 4:**

How likely are you to recommend this hospital to friends and family if they needed similar care or treatment?

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

The phrase ‘if they needed similar care or treatment to me’ was well received, and essential to the children's understanding of the question. ‘Suggesting’ or ‘recommending’ a hospital in examples 3 and 4 caused some confusion. Some young patients thought it was odd to recommend their friends/family to a hospital and others felt that it would depend on the reason for their hospital admission or their medical condition. A few participants felt that they would not recommend a
hospital to their friends or family, even if they did have a positive experience. This replicates findings from testing with adults (Graham & MacCormick, 2012).

“Depends on what condition, if it was a trauma or gastro or like surgical, I’d say yeah… for gastro it’s the best ward to treat my condition in the whole world so obviously I’m going to come here but other conditions, I don’t know anything about other conditions.”

“Well, none of my friends have any conditions so the only reason they’d probably be in the hospital was if they got hit by a car and they wouldn’t have time to consult me on which is the best service…well, you just get hit by a car and then you’re like, oh by the way, I’d just need to know which hospital you’d recommend.”

“I don’t really know if I would recommend the hospital in the first place, I’d be surprised if you’re given a choice of where you could go, usually it’s… Well I can’t see myself in the situation where you’d be recommending hospitals.”

Response options

Some focus group participants, particularly the younger children aged under 10 years old, preferred fewer responses to choose from. However all participants could still answer with more response options. Older children in particular felt that a greater number of response options would allow for a more accurate portrayal of their response. Using more than three response options reduced the extent to which participants selected the top option only. The consequence of this ‘ceiling effect’ identified with few response options would be that when implemented, the question may not distinguish between good and poor experience if everyone provides the same ‘top’ answer. However, it is important to note that the extent to which scales of different lengths are fully utilised have not been measured or quantified.

Question examples 1 and 2 were considered to have very similar wording, however the response options were preferable in example 1.

6 http://www.nhssurveys.org/Filestore/reports/Overarching_questions_for_patient_surveys_v3.pdf
Stage 2: Question Development

Various versions of the FFT were drafted using the image preferences identified in the focus group. These are displayed in figure 5 and were presented to children in the ward interviews.

Figure 5: Ward Interview Questions

1a. I would say this is a good hospital for my friends & family to be looked after in, if they needed similar treatment or care to me.
   - I agree a lot
   - I agree a bit
   - I am undecided
   - I disagree a bit
   - I disagree a lot
   - I don’t know

1b. I would say this is a good hospital for my friends & family to be looked after in, if they needed similar treatment or care to me.
   - I agree a lot
   - I agree a bit
   - I am undecided
   - I disagree a bit
   - I disagree a lot
   - I don’t know

2a. Is this a good hospital for your friends & family to go to, if they needed to go to hospital?
   - Yes, definitely
   - Sort of
   - No
   - Don’t know

2b. Is this a good hospital for your friends & family to go to, if they needed to go to hospital?
   - Yes, definitely
   - Sort of
   - No
   - Don’t know

3a. If your friends and family needed to go to hospital, would you suggest this hospital to them?
   - Yes, definitely
   - Probably
   - No
   - Don’t know

3b. If your friends and family needed to go to hospital, would you suggest this hospital to them?
   - Yes, definitely
   - Probably
   - No
   - Don’t know

4a. How likely are you to recommend this hospital to friends and family if they needed similar care or treatment?
   - Extremely likely
   - Likely
   - Neither likely nor unlikely
   - Unlikely
   - Extremely unlikely
   - Don’t know

4b. How likely are you to recommend this hospital to friends and family if they needed similar care or treatment?
   - Extremely likely
   - Likely
   - Neither likely nor unlikely
   - Unlikely
   - Extremely unlikely
   - Don’t know
Stage 3: Ward Interviews

A total of eight young patients agreed to be interviewed on the ward. Participants were aged 8-15 years old from a range of ethnic backgrounds and equal gender representation – please refer to Table 2. Patients’ length of stay ranged from a day case visiting for appointments up to a two-week visit.

Table 2: Ward interview participants

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Type of visit</th>
<th>Length of stay (up to the day of the ward interview)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>15</td>
<td>Female</td>
<td>Inpatient</td>
<td>2 days</td>
</tr>
<tr>
<td>2</td>
<td>15</td>
<td>Female</td>
<td>Inpatient</td>
<td>2 weeks</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
<td>Male</td>
<td>Inpatient</td>
<td>In and out over last 8 months</td>
</tr>
<tr>
<td>4</td>
<td>14</td>
<td>Male</td>
<td>Inpatient</td>
<td>2 weeks</td>
</tr>
<tr>
<td>5</td>
<td>11</td>
<td>Male</td>
<td>Day case</td>
<td>Day admission only</td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>Female</td>
<td>Day case</td>
<td>Day admission only</td>
</tr>
<tr>
<td>7</td>
<td>9</td>
<td>Male</td>
<td>Day case</td>
<td>Day admission only</td>
</tr>
<tr>
<td>8</td>
<td>13</td>
<td>Female</td>
<td>Inpatient</td>
<td>2 weeks</td>
</tr>
</tbody>
</table>

Young patients felt that the word ‘suggest’ (example 3) was more easily understood than ‘recommend’ (example 4). As with the focus group, the interviews highlighted that the phrase ‘if they needed similar care or treatment’ was considered an important part of the question for most children, particularly for patients requiring specialist care at the Royal London Hospital; otherwise they would recommend a hospital closer to home.

“It really depends on what’s wrong with them, doesn’t it?”

“I don’t know, I have not been to many hospitals and I have been here only for a day, I cannot have a big opinion.”

Views on the number of response options reflected the focus group findings. Although some participants had a preference for fewer response options for ease of completion, others felt a greater number of responses allowed them to give a more accurate response. The response options ‘probably’ (example 3) and ‘sort of’ (example 2) appeared vague. In example 1, many young patients could not distinguish between the response options ‘undecided’ and ‘I don’t know’:

“Isn’t undecided and don’t know the same thing?”

When the large images were discussed, the Monkey pictures were most preferred by young and older patients’ alike, echoing focus group findings. Pictures of Monkey in a hospital setting were seen as most appropriate.

Similar to the focus group findings, discussions about the response scale images revealed that the colourful smiley faces were more helpful than the Monkey scale to illustrate response options, with traffic light system colours guiding their choice.

“Choosing [smiley] faces is easier…it would be easier to put a mark on there [scale]”
In summary, findings from the focus groups and interviews demonstrated preference for version 1a of the question, presented with the smiley face scale and 5 response options. Figure 6 displays the final version that was compiled onto a friends and family test form for cognitive testing.

**Figure 6: the Friends and Family Test question**

I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me.
Please tick one only.

- [ ] I agree a lot
- [ ] I agree a bit
- [ ] I disagree a bit
- [ ] I disagree a lot
- [ ] I can't decide/ I don't know

**Stage 4: Cognitive Testing**

Cognitive interview participants ranged from 4-14 years old and were from a range of ethnic backgrounds. Patients’ length of stay ranged from day case to around two months, with the majority of patients experiencing repeat visits to the Royal London Hospital or surrounding hospitals. Participant characteristics are displayed in table 3. All participants were interviewed alongside their parent/carer. However, children were actively encouraged to express their views and the interviewer only asked for parental input where absolutely necessary.

**Table 3: Cognitive interview participants**

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Length of stay</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14</td>
<td>Male</td>
<td>4 days</td>
</tr>
<tr>
<td>2</td>
<td>11</td>
<td>Female</td>
<td>2 days</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>Male</td>
<td>1 day</td>
</tr>
<tr>
<td>4</td>
<td>13</td>
<td>Male</td>
<td>5 days</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>Female</td>
<td>3 days</td>
</tr>
<tr>
<td>6</td>
<td>14</td>
<td>Female</td>
<td>2 months</td>
</tr>
<tr>
<td>7</td>
<td>14</td>
<td>Male</td>
<td>4 days</td>
</tr>
<tr>
<td>8</td>
<td>10</td>
<td>Female</td>
<td>9 weeks</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td>Female</td>
<td>3 days</td>
</tr>
<tr>
<td>10</td>
<td>11</td>
<td>Male</td>
<td>6 days</td>
</tr>
<tr>
<td>11</td>
<td>7</td>
<td>Female</td>
<td>2 days</td>
</tr>
<tr>
<td>12</td>
<td>10</td>
<td>Male</td>
<td>1 day</td>
</tr>
</tbody>
</table>
The majority of questions were easily understood by respondents (both young and older children and parents/carers). Feedback on the different sections of the form are outlined below.

**Instructions**

The initial instructions detailing how to complete the survey form were read and understood by most, with only the younger participants (4-7 years) relying on their parent for help. There was some confusion in interpreting instructions asking parents/carers to complete a separate form if they also wished to give their views. In one case, the parent/carer did not understand the instruction that they were able to complete a separate form despite reading it aloud to their child.

Another problem identified during cognitive interviews was that the instructions for the online option were placed at the end of the survey form, resulting in participants completing the paper form before realising there was an option to complete online.

The format of the instructions were amended based on the above feedback:

- Instructions were listed as bullet points for clearer presentation, and the text was made more concise.
- An additional bullet point was added to the instructions on the first page to highlight the online option – asking responders to turn over the page for specific instructions on accessing this.

**Date**

The date question (see Figure 7) used to capture basic demographic data was slightly redesigned because some of the younger children mistook the DDMMYYYY guidance as something they should trace over, or was missed as it looked as if it was already completed. Therefore the faint ‘DDMMYYYY’ grey text was removed from within the response boxes and placed underneath. For additional clarity, an example of a completed date was added above the question.

![Figure 7: Date question](image)

**FFT question**

The majority of participants understood the FFT question (see Figure 5), and in most instances it was completed by the young person and unaided by parents/carers. When asked to explain their choice, it became clear that participants comprehended the question and selected appropriate responses. Some of the younger children found it a difficult sentence to read aloud due to its length, however they managed to read and respond with minimum parental input. Only one parent/carer had difficulty reading the question and this is likely to be because English was not their first language. In this instance, the parent/carer couldn’t explain to the child in a way that
they could understand, and the researcher ‘translated’ the response options into ‘I like it a lot, I like it a bit’ before the child was able to point to an option they felt suitable.

Overall, it was felt that the FFT question was interpreted successfully and needed no further changes.

**Freetext follow-up questions**

Two open-ended questions were asked following the FFT – one asking what was good about the hospital visit and the other asking if there was anything that could have been better. Providing written comments appeared more challenging for the younger children, however parents/carers were able to assist in completing responses that the child had verbalised.

Some text at the bottom of the freetext boxes explained how the comments might be publicised, and asked respondents for permission to use their comments (with an option to opt-out by ticking a box). This was missed by over half of interviewees. It was therefore moved to the top of the freetext box. Furthermore the text was shortened and also the font size was slightly increased. It also became clear that the tick box should be moved to the end of the sentence in order for children to read the full sentence before deciding whether to tick the box or not.

**Demographic Questions**

The demographic questions (age and gender) were completed and understood with ease, with participants selecting from the responses provided without issues.

**Form Design**

Patients commented on the layout, pictures and colours during the cognitive tests. They were fond of the Monkey images and colours, and none of the children disliked the look of the form. They were appreciative of the relatively short length of the form compared to longer surveys they had been asked to complete in the past.

Please refer to Appendix 1 for the pre-cognitive testing version of the form, and Appendix 2 for the post-cognitive testing version following the amendments outlined above.
Stage 5: Pilot

The survey form was amended according to the cognitive interview feedback. An online version of the survey was then created in the survey software package Snap (version 11), to mimic the paper version. The pilot results and response rates for the six participating paediatric wards across the two NHS Trusts are outlined below. The survey data for both Trusts have been combined, however response rates are displayed at site and at ward level.

Format of Results

Results are presented in the form of response rates, respondent characteristics, and results for the FFT question (overall and by patient demographics). Due to the methodology chosen for this survey (self-completion), there are inevitably a number of missing responses for each question. The percentage calculations throughout the report exclude respondents that did not answer. Full frequency tables are included at the end of the report (Appendix 4), which display how many people answered, and the proportion of patients that selected each response option. Due to rounding percentages to contain no decimals, the total count of these percentages may not always add up to exactly 100%.

Survey Responses

At the Royal London Hospital, a total of 307 forms were completed across the three participating wards, compared to 365 completions at Southampton Children’s Hospital. Each Trust had a higher number of responses from their day wards relative to inpatient wards – perhaps unsurprising given the increased number of patients discharged from day wards. Full response details are displayed in Table 4 below.

Table 4: Survey responses by ward

<table>
<thead>
<tr>
<th>Hospital /Ward Name</th>
<th>Ward Type</th>
<th>Average number of patients p/month*</th>
<th>Number of surveys sent</th>
<th>Number of completed surveys (6 wks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal London Hospital: total</td>
<td></td>
<td>1081</td>
<td>1440</td>
<td>307</td>
</tr>
<tr>
<td>6B</td>
<td>Day Ward</td>
<td>650</td>
<td>800</td>
<td>175</td>
</tr>
<tr>
<td>7E/7C PASSU</td>
<td>Short Stay Inpatient</td>
<td>316</td>
<td>470</td>
<td>69</td>
</tr>
<tr>
<td>7F</td>
<td>Inpatient</td>
<td>115</td>
<td>170</td>
<td>63</td>
</tr>
<tr>
<td>Southampton Children's Hospital: total</td>
<td></td>
<td>681</td>
<td>1020</td>
<td>365</td>
</tr>
<tr>
<td>E1</td>
<td>Inpatient</td>
<td>83</td>
<td>120</td>
<td>77</td>
</tr>
<tr>
<td>JA**</td>
<td>Day Ward</td>
<td>410</td>
<td>600</td>
<td>211</td>
</tr>
<tr>
<td>G3</td>
<td>Inpatient</td>
<td>188</td>
<td>300</td>
<td>77</td>
</tr>
<tr>
<td>Total (both Trusts)</td>
<td></td>
<td>1762</td>
<td>2460</td>
<td>672</td>
</tr>
</tbody>
</table>

* Please note that this is an approximate number of patients discharged per month which was used to estimate how many forms should be sent to each ward. It is not the final number of patients discharged over the fieldwork period.

**John Atwell Day Ward
The majority of responses were completed using the paper form, with only five responses completed online.

**Respondent Characteristics**

The pilot yielded a similar number of responses from male and female patients, although there was a slightly greater number of forms completed by males (54%; n=350) than females (46%; n=304). The age group 0-2 years had the highest volume of survey completions overall, accounting one quarter (25%; n=157) of all responses, followed by 12-15 years who formed 22% (n=140) of respondents. The age groups 16-18 years (7%; n=43) and those aged 9-11 years (11%; n=70) accounted for the smallest proportion of questionnaires returned. Please note that without details on the population profile, it is not possible to infer whether or not the responses are typical of the patient population during the fieldwork period.

Full details of respondent characteristics are displayed in Table 5.

**Table 5: Respondent Characteristics**

<table>
<thead>
<tr>
<th>Respondent characteristics</th>
<th>Number (n)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>350</td>
<td>54%</td>
</tr>
<tr>
<td>Female</td>
<td>304</td>
<td>46%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>654</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Age of young patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 years old</td>
<td>157</td>
<td>25%</td>
</tr>
<tr>
<td>3-5 years old</td>
<td>120</td>
<td>19%</td>
</tr>
<tr>
<td>6-8 years old</td>
<td>96</td>
<td>15%</td>
</tr>
<tr>
<td>9-11 years old</td>
<td>70</td>
<td>11%</td>
</tr>
<tr>
<td>12-15 years old</td>
<td>140</td>
<td>22%</td>
</tr>
<tr>
<td>16-18 years old</td>
<td>43</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>626</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Respondent – who completed the survey form</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child who went to hospital</td>
<td>169</td>
<td>26%</td>
</tr>
<tr>
<td>Parent/carer of child</td>
<td>346</td>
<td>53%</td>
</tr>
<tr>
<td>Child &amp; parent/ carer together</td>
<td>143</td>
<td>22%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>658</td>
<td>100%</td>
</tr>
</tbody>
</table>
More than half of all survey forms were completed by parent/carers (53%; n=346), and over one quarter (26%; n=169) by the child who went to hospital. The remaining 22% (n=143) were filled in by both the child and parents/carer. Please note that in some instances, there may have been two forms completed on behalf of the same patient – i.e. the parent and the patient of the same family, since the form instructions advises that both complete a separate form if both wish to provide feedback.

Figure 8 indicates the respondent type (i.e. who completed the survey form; the child, parent/carer, or both together) according to the age of the young patient.

**Figure 8: Respondent type by age of patient**

Unsurprisingly, almost all forms returned by the 0-2 years group were completed by the parent/carer of the child (96%; n=149). As expected, child involvement in questionnaire completion increased with age. Children aged 9 years and over were more likely to complete a form themselves than younger patients. However, since the survey encourages both parent and child to complete a separate survey form should they both wish to give their views, it is not possible to differentiate the proportion of parents that completed the form on behalf of their child from those who completed a form in addition to their child.
The Friends and Family Test Question

The FFT question was asked to children in the following format:

I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me.

Please tick one only.

☐ I agree a lot
☐ I agree a bit
☐ I disagree a bit
☐ I disagree a lot
☐ I can't decide/ I don't know

An overwhelming number of respondents chose ‘I agree a lot’ or ‘I agree a bit’ supporting the statement that the hospital they attended was a good place for their friends and family to be treated in if they required similar care or treatment. Table 6 shows the number and percent of answers for each response.

Table 6: Responses to the Friends and Family Test Question (all respondents; n = 665)

“I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me”

<table>
<thead>
<tr>
<th>Response</th>
<th>Number of respondents</th>
<th>% of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree a lot</td>
<td>600</td>
<td>90%</td>
</tr>
<tr>
<td>I agree a bit</td>
<td>51</td>
<td>8%</td>
</tr>
<tr>
<td>I disagree a bit</td>
<td>4</td>
<td>1%</td>
</tr>
<tr>
<td>I disagree a lot</td>
<td>1</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>I can't decide/ I don't know</td>
<td>9</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>665</td>
<td>100%</td>
</tr>
</tbody>
</table>

90% (n=600) of all respondents ‘agreed a lot’ with the statement that the hospital they stayed in was a good place for their friends and family to be looked after in, and 8% (n=51) agreed with this ‘a bit’. Only four respondents (1%) ‘disagreed a bit’ and just one person (<1%) ‘disagreed a lot’. Nine responders were undecided or did not know.
The FFT guidance currently requires NHS Trusts to score and report the FTT question as follows:
- The percent responding ‘I agree a lot’ and ‘I agree a bit’ (of all respondents) = 98% (n = 651)
- The percent responding ‘I disagree a lot’ and ‘I disagree a bit’ (of all respondents) = 1% (n = 5)

**Table 7: Responses to the Friends and Family Test Question (NHSE)**

“I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me”

<table>
<thead>
<tr>
<th>Response</th>
<th>Number of respondents (n)</th>
<th>Percentage of respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree <em>(I agree a lot; I agree a bit)</em></td>
<td>651</td>
<td>98%</td>
</tr>
<tr>
<td>Disagree <em>(I disagree a bit; I disagree a lot)</em></td>
<td>5</td>
<td>1%</td>
</tr>
<tr>
<td>I can’t decide/ I don’t know</td>
<td>9</td>
<td>1%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>665</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
**FFT Responses by Ward Type**

Responses to the FFT by ward type (inpatient or day case) were assessed. A majority of respondents who were treated in the day case wards ‘agreed a lot’ (93%; n= 365) or ‘agreed a bit’ (5%; n=19) with the statement that the hospital was a good place for friends and family if they needed similar care or treatment. Only two day case patients (<1%) ‘disagreed’ with the FFT statement. Compared to day cases, fewer inpatient respondents (87%; n=187) ‘agreed a lot’, with a slightly higher proportion (10%; n=22) ‘agreeing a bit’. Please refer to figure 9 for full information, however please note that statistical testing has not been performed to address whether any gender differences in responses to the FFT question are significant.

**Figure 9: Responses to the Friends and Family Test Question by Ward Type**

“I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me”

![Bar chart showing responses to the FFT by ward type](chart.png)

*Base sizes: n=543 (Overall), n=187 (Inpatient), n=356 (Day Case)*
FFT responses by Gender

There similar responses to the FFT question by gender of the patient, with 90% (n=314) of males and 91% (n=274) of females ‘agreeing a lot’ that the hospital was a good place for their friends and family – please refer to figure 10. Again please note that statistical significance testing has not been conducted.

Figure 10: Responses to the Friends and Family Test Question Score by Gender

“I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me”
FFT responses by Age

Small differences in responses to the FFT question by age were revealed, however significance testing has not been conducted to determine whether age differences are statistically significant. The age groups with the most positive responses, indicated by the greatest proportion selecting the most positive response option (‘I agree a lot’) were 3-5 year olds (93%; n=112) and 9-11 year olds (94%; n=66). In comparison, the groups with the lowest percentage of patients agreeing a lot were 12-15 years (88%; n=122) and 6-8 years (89%; n=85).

Figure 11: Responses to the Friends and Family Test Question by Age Group

“I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me”
FFT by Responder Type (parent/child)

Responses to the FFT were assessed by who answered the survey form (i.e. parent, child or parent and child together) and revealed only minor differences. Surveys completed by children did indicate a slightly lower percentage strongly agreeing to the hospital being good for their friends and family (88%; n=147) compared with forms completed by parents (91%; n=313) or by the parent and child together (92%; n=130), but these differences were minimal. Please refer to the below figure for full information. However, please note that these differences are also likely to be influenced by age differences between the groups.

Figure 12: Responses to the Friends and Family Test Question by Respondent

“I would say this is a good hospital for my friends and family to be looked after in, if they needed similar treatment or care to me”
Freetext Comments

Respondents were given the option to give comments to explain more about their hospital visit. Respondents were first asked ‘What was good?’ about their stay and secondly ‘What could we do better?’.

Many respondents left an answer to the freetext questions to explain more about their hospital visit. Overall, 629 participants provided comments to the question ‘What was good?’ and 424 comments were given to the question ‘What could we do better?’. Freetext responses were more informative than the FFT scores in terms of identifying areas for improvement in addition to highlighting positive aspects of care. The FFT can therefore be used as a means to gather constructive comments which proved to be more useful than the quantitative data from the FFT score alone, with its profound ceiling effect.

The key themes emerging from the freetext comments are summarised below along with some example quotes (only displayed for those who agreed to their comments being shared). Any identifying information such as patient or staff names have been removed.

**Staff**

Many of the positive freetext comments referred to hospital staff. Nurses, doctors, anaesthetists, and play workers as well as general staff were praised for their friendliness and helpfulness, their caring and courteous attitude, and good communication.

‘They talked me through everything and [NAME] looked after me really well.’

‘The standard of nursing and medical care was excellent. Good communication with us and our daughter at all times.’

‘Fantastic doctors. Night nurses very thoughtful. Support workers and helpers fantastic. Physio support amazing.’

‘The staff are lovely and really supportive and kind.’

‘The nurses/ doctors/carers are really nice and caring.’

‘All the staff are very helpful and friendly.’

However, some commented on staff not introducing themselves to the patients and parent/carer.

‘Not everyone introduced themselves. One Dr on assessment didn’t check he had the correct patient.’

‘Junior Doctor (Not all) please introduce yourself to mum before you do any procedure on their babies.’

**Hospital environment**

The hospital environment was also praised.

‘[It was good] to see all the beds looking tidy.’

‘Everything. Friendly staff, clean environment, clean beds. Quick service and updates on my child’s progress.’

‘Friendly staff. Good facilities. Cleanliness.’

‘The nurse and doctor very nice. The room are nice and clean.’
For many children, a hospital experience can be frightening due to the unfamiliar environment and lack of understanding about what will happen to them during their time in hospital. The comments indicated that patients and parents were very appreciative of being made to feel safe, welcome and comfortable.

‘The hospital was good because I was scared at first, but was fine afterwards too.’
'I found it good being in hospital because I got lots of support and felt really safe.'

‘The bed was comfortable I got lots of stickers and a special surprise. The nurses were really nice and I wasn't frightened at all this time. I loved painting and playing games with the hospital teaching assistant and play worker.’

‘My son loved the jeep drive to theatre. Turns the surgery experience into fun for young kids rather than fear. Well done.’

Facilities

Another common theme from the positive comments were hospital facilities, including playrooms, entertainment and toys. The activities available – e.g. a Nintendo Wii games console, a football table, and painting – were highly appreciated by the patients. They made their visits more pleasant and took their mind off of the reason they were in hospital:

‘I found it really good because they had a playroom, so when I was waiting I could do some colouring and painting. It was also good because I was able to play on an iPad before my operation’

‘The play workers bought me paint to my bed and pictures to paint’

‘I got to play games and watch TV’

‘I liked the way the play workers check on every patient and check if they’re bored and they give something to entertain the patient’

‘They had an X-box and it’s got fun toys’

However, suggestions for improvement related to car parking facilities, both the spaces being too narrow e.g. for a child who has a cast, and the fees that have to be paid for the parking:

‘Car parking- spaces are quite narrow and [it is] hard to get child (especially in a cast) out of the car.’
‘Discount for car park fees if patient has operation’
‘Need a bigger car park.’

Waiting times

Both parents and children highlighted long waiting times before operations and procedures. It is not always communicated to the parents how long the waiting time would be. Parents highlighted that it is difficult for children to wait for a long time, particularly when they are very young, or unable to eat or drink in advance of their procedure.

‘Tell patient that they are likely to be waiting for hours so they can prepare and bring things with them’
‘Info day before admission e.g. what can be expected, potential waiting times and possible discharge times’

‘The waiting time for young children especially when they are not allowed to eat or drink and the time is so long to wait for treatment from the time given’
Food

Some children commented positively on the hospital food:

‘All the staff, tuna sandwiches, all the things to do’

‘Yes. I liked the toast.’

‘The yummy toast and biscuits.’

However, some respondents felt that there should be a wider range of choices and that the quality should be improved.

‘Hospital food could always do with being improved!’

‘The food could be better because some of the meals aren’t that nice and are on the borderline of being inedible’

‘Quality of food, and more varied menus.’

‘The food was awful I made my mum buy me food every day!’

‘Dinner/lunch same thing every day was here one week refused to eat by 3rd day. Need better food.’

Another food-related issue was the (lack of) availability for parents to access food/ drinks, e.g. lack of coffee machines/ vending machine, discounts in hospital restaurant and breakfast for parents who stay overnight.

‘Coffee machine for carers and parents even around the paediatric ward’

‘Parent vending machine on wards would be grateful for those parents whose children won't let them leave’

‘Mummy could have had some food!!’

‘Refreshments so parents can stay on ward’

‘Serve breakfast for the parents that are staying overnight’.

Word clouds

One way of presenting freetext comments from open-ended questions is by using word clouds. These provide a visualisation of the verbatim comments supplied by those who respond to a freetext question. Word clouds perform a count on the frequency of words to produce an image. The more a word gets mentioned, the bigger the size of the word in the image. All of the words are adjusted proportionately and randomly placed within the cloud. A word cloud is displayed below for each of the two open-ended questions on the survey form.
What was good?

What could be better?

When the respondents were asked what the hospital should improve on, many commented with ‘Nothing’, which reflects the positive experience many of them had during their hospital stay. Many of the remaining comments related to waiting times and food.
Conclusions and Recommendations

Conclusions

Children and young people are entitled, willing, and able to give their views about their healthcare. Any feedback tool for young patients must be developed & cognitively tested with young patients to ensure that it is child-friendly, accessible and appealing to this group. The qualitative stages of this research indicated that children and young people preferred a ‘young person friendly’ version of the FFT over the adult question, and this was shown to yield an acceptable number of response across the pilot wards. Uptake of the online version of the survey was extremely low. This might be a consequence of lack of WiFi facilities over the two pilot hospital sites. Hospitals with WiFi may wish to offer an online option alongside a paper version, particularly since children and young people are generally au fait with technology platforms. However, until this approach is tested in WiFi wards, it remains unclear whether an online version would attract a substantial number of responses for the set-up and hosting to be worthwhile and cost-effective.

Responses to the FFT question were overwhelmingly positive across two hospital sites. This may be partly due to response bias whereby patients do not wish to give negative feedback in the presence of healthcare staff on the wards: existing research has demonstrated significant differences in adult FFT responses by the mode of administration (Sizmur et al, 2015).

Demographic factors did not appear to influence responses to the FFT. This is inconsistent with adult populations, for example where women have shown to give less positive ratings than men (Sizmur et al, 2015). However, demographic effects should be further explored in children and young people using larger sample sizes and statistical significance testing.

The FFT guidance for children and young people specifies that since the views of children and their families or carers can often differ, consideration should be given to obtaining both views where possible. For this reason, our recommended form asks that the child and parent/carer complete separate forms if they both wish to provide feedback. This is useful if the aim is to obtain the maximum volume of feedback and particularly if written comments are to be used as qualitative evidence. However, there are multiple problems with this approach:

- it does not allow identification of how many parents and children of same family answer. The pilot showed that over 50% of forms were completed by parents/carers alone. However since the form encourages both parents and children to feedback via separate forms, we do not know what proportion of parent completions were accompanied by a completed form from their child. More specifically, the parent completions will not all be instances where a parent

---

completed the survey on behalf of their child, instead it may be that they took part in addition to their child;

- there may be an additional source of bias in FFT scores if double responses are more likely when care is either particularly good or particularly bad – one might hypothesise that children and parents might be more likely both to respond if care largely differs from expectations (e.g. the leverage-Salience theory of survey response; Groves et al, 2000);
- it is not possible to compare parent and child responses as part of dyads.

Regarding the reporting of FFT question data, from October 2014 there were changes made to the way the FFT score is reported. Instead of calculating a Net Promoter Score, two percentage measures are now calculated and reported:

(i) The total percent (of all responses) that recommend (i.e. the percentage answering ‘agree a lot’ and ‘agree a bit’);
(ii) The total percent (of all responses) that do not recommend (i.e. the percentage answering ‘disagree a lot’ and ‘disagree a bit’).

Combining the two positive responses resulted in 98% agreeing that the hospital was a good place for their friends and family. These ceiling effects result in most responders having positive feedback, therefore the score did not distinguish well between positive and poor experience. Responses to the FFT alone therefore cannot be used to drive improvement, with 98% of all pilot respondents agreeing (a lot or a bit) that the hospital they stayed in is a good place for their friends and family to be looked after.

The free text comments were useful for providing insight into specific aspects of hospital care – both positive and negative experiences. Therefore moving beyond the FFT question and analysing the free text comments can identify areas for improvements in paediatric care provision, which is consistent with existing reviews on the adult FFT (Graham, 2014; Picker Institute Europe, 2014).

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9 http://www.hsj.co.uk/home/commissioning/opinion/the-friends-and-family-test-works-best-if-we-forget-about-scores/5071200.article#.VOyaHaNFDIU
Recommendations

The key recommendations for children and young people’s FFT are as follows:

- All children and young people should be offered a ‘young person friendly’ version of the FFT that has been developed and cognitively tested with children. Instead of initially offering them the adult version, it is recommended that only a child-friendly version is offered across paediatric care settings, using the question outlined in the current report. We note that the scale length is different to the adult question, but acknowledge that variation is permitted in the national guidance.

- Our scale is recommended because the testing demonstrated that it was the most effective in terms of encouraging children to respond, and is consistent with use of the FFT not as a statistical measure but rather as a means of gathering large volumes of free text comments. The pilot demonstrated that the comments left alongside the FFT from both young patients and parents/carers were both informative and useful. In line with NHS England’s national guidance, free text comments should be sought from as many children as possible to allow providers to make the best use of their FFT feedback.

- In keeping with national guidance, the FFT should not be used for statistical comparison between organisations if there is no standardised methodology (i.e. inconsistency in how and when the question is asked). When implemented in real-time settings, the FFT question should be asked in the absence of hospital staff or people that provide direct care to patients, to avoid response bias.

- The FFT score should report on individual categories to capture the percentages responding to each of the response options individually (agree a lot, agree a bit, disagree a bit, and disagree a lot). However, this approach would not guarantee the usefulness of the quantitative data given the strong ceiling effects that were observed.

- Recommended FFT questions for children and young people across community, ambulance and GP settings, and for adults and young people with a learning disability, should be developed and tested in the same way with the respective patient populations.
Acknowledgements

Picker Institute Europe would like to acknowledge:

- Barts Health NHS Trust for part-funding the project and for working collaboratively with the Picker Institute to conduct the qualitative research.

- Barts Health NHS Trust (Royal London Hospital) and Southampton Children’s Hospital for volunteering to be pilot sites and efficiently collating completed survey forms across their selected wards.

- Helen Sadler and Monkey Wellbeing for access to Monkey images for presenting in the qualitative stages, and for allowing use of one of the images on the final form.

- Birmingham Children’s Hospital and the ‘making the FFT inclusive’ – children and young people section of the revised NHS England guidance for the existing recommended question for children and young people.
Appendix 1: FFT form – Pre-cognitive testing version

*The following fields are pre-printed prior to delivering to wards: Name of ward / department, website address, online ID and QR code.*
Appendix 2: FFT form – Pilot/ post-cognitive testing version

*The following fields are pre-printed prior to delivering to wards: Name of ward / department, website address, online ID and QR code.*
Appendix 3: Final FFT form post-pilot

*The following fields are pre-printed prior to delivering to wards: Name of ward / department, website address, online ID and QR code.
# Appendix 4: Pilot Frequency Tables

## Frequency Count: Ward type

<table>
<thead>
<tr>
<th>Ward Type</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Case</td>
<td>386</td>
<td>64.0</td>
</tr>
<tr>
<td>Inpatient</td>
<td>217</td>
<td>36.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>603</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td><strong>69</strong></td>
<td></td>
</tr>
</tbody>
</table>

## Frequency Count: Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>350</td>
<td>53.5</td>
</tr>
<tr>
<td>Female</td>
<td>304</td>
<td>46.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>654</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td><strong>18</strong></td>
<td></td>
</tr>
</tbody>
</table>

## Frequency Count: Age Group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 yrs</td>
<td>157</td>
<td>25.1</td>
</tr>
<tr>
<td>3-5 yrs</td>
<td>120</td>
<td>19.2</td>
</tr>
<tr>
<td>6-8 yrs</td>
<td>96</td>
<td>15.3</td>
</tr>
<tr>
<td>9-11 yrs</td>
<td>70</td>
<td>11.2</td>
</tr>
<tr>
<td>12-15 yrs</td>
<td>140</td>
<td>22.4</td>
</tr>
<tr>
<td>16-18 yrs</td>
<td>43</td>
<td>6.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>626</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td><strong>46</strong></td>
<td></td>
</tr>
</tbody>
</table>
Frequency Count: Respondent type

<table>
<thead>
<tr>
<th>Main person answering questions</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child who went to hospital</td>
<td>169</td>
<td>25.7</td>
</tr>
<tr>
<td>The parent or carer of the child who went to hospital</td>
<td>346</td>
<td>52.6</td>
</tr>
<tr>
<td>Both child and parent or carer together</td>
<td>143</td>
<td>21.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>658</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td><strong>14</strong></td>
<td></td>
</tr>
</tbody>
</table>

FFT Question: Frequency Table

<table>
<thead>
<tr>
<th>FFT Question</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree a lot</td>
<td>600</td>
<td>90.2</td>
</tr>
<tr>
<td>I agree a bit</td>
<td>51</td>
<td>7.7</td>
</tr>
<tr>
<td>I disagree a bit</td>
<td>4</td>
<td>.6</td>
</tr>
<tr>
<td>I disagree a lot</td>
<td>1</td>
<td>.2</td>
</tr>
<tr>
<td>I can't decide / I don't know</td>
<td>9</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>665</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
<td><strong>7</strong></td>
<td></td>
</tr>
</tbody>
</table>

FFT Question: By ward type

<table>
<thead>
<tr>
<th>FFT Question * Ward Type Crosstabulation</th>
<th>Ward Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree a lot</td>
<td>Count</td>
</tr>
<tr>
<td>Day Case</td>
<td>356</td>
</tr>
<tr>
<td>Inpatient</td>
<td>187</td>
</tr>
<tr>
<td>I agree a bit</td>
<td>Count</td>
</tr>
<tr>
<td>Day Case</td>
<td>19</td>
</tr>
<tr>
<td>Inpatient</td>
<td>22</td>
</tr>
<tr>
<td>I disagree a bit</td>
<td>Count</td>
</tr>
<tr>
<td>Day Case</td>
<td>1</td>
</tr>
<tr>
<td>Inpatient</td>
<td>2</td>
</tr>
<tr>
<td>I disagree a lot</td>
<td>Count</td>
</tr>
<tr>
<td>Day Case</td>
<td>1</td>
</tr>
<tr>
<td>Inpatient</td>
<td>0</td>
</tr>
<tr>
<td>I can't decide / I don't know</td>
<td>Count</td>
</tr>
<tr>
<td>Day Case</td>
<td>4</td>
</tr>
<tr>
<td>Inpatient</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>Count</td>
</tr>
<tr>
<td>Day Case</td>
<td>381</td>
</tr>
<tr>
<td>Inpatient</td>
<td>215</td>
</tr>
</tbody>
</table>
### FFT Question: By gender

<table>
<thead>
<tr>
<th>FFT Question * Gender Crosstabulation</th>
<th>Gender</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Male</strong></td>
<td><strong>Female</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I agree a lot</td>
<td>Count</td>
<td>314</td>
<td>274</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% within Gender</td>
<td>90.2%</td>
<td>90.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I agree a bit</td>
<td>Count</td>
<td>28</td>
<td>21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% within Gender</td>
<td>8.0%</td>
<td>7.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I disagree a bit</td>
<td>Count</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% within Gender</td>
<td>6.0%</td>
<td>3.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I disagree a lot</td>
<td>Count</td>
<td>1</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% within Gender</td>
<td>3.0%</td>
<td>0.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can’t decide / I don’t know</td>
<td>Count</td>
<td>3</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% within Gender</td>
<td>9.0%</td>
<td>2.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>Count</td>
<td>348</td>
<td>302</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% within Gender</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### FFT Question: By Age Group

<table>
<thead>
<tr>
<th>FFT Question * Age Group Crosstabulation</th>
<th>Age Group</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-2 yrs</td>
<td>3-5 yrs</td>
<td>6-8 yrs</td>
<td>9-11 yrs</td>
<td>12-15 yrs</td>
<td>16-18 yrs</td>
</tr>
<tr>
<td>I agree a lot</td>
<td>Count</td>
<td>141</td>
<td>112</td>
<td>85</td>
<td>66</td>
<td>122</td>
</tr>
<tr>
<td></td>
<td>% within Age Group</td>
<td>89.8%</td>
<td>93.3%</td>
<td>89.5%</td>
<td>94.3%</td>
<td>87.8%</td>
</tr>
<tr>
<td>I agree a bit</td>
<td>Count</td>
<td>12</td>
<td>8</td>
<td>8</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>% within Age Group</td>
<td>7.6%</td>
<td>6.7%</td>
<td>8.4%</td>
<td>2.9%</td>
<td>9.4%</td>
</tr>
<tr>
<td>I disagree a bit</td>
<td>Count</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>% within Age Group</td>
<td>1.3%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>1.4%</td>
<td>0.0%</td>
</tr>
<tr>
<td>I disagree a lot</td>
<td>Count</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>% within Age Group</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>.7%</td>
</tr>
<tr>
<td>I can’t decide / I don’t know</td>
<td>Count</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>% within Age Group</td>
<td>1.3%</td>
<td>0.0%</td>
<td>2.1%</td>
<td>1.4%</td>
<td>2.2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>Count</td>
<td>157</td>
<td>120</td>
<td>95</td>
<td>70</td>
<td>139</td>
</tr>
<tr>
<td></td>
<td>% within Age Group</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
### FFT Question: By respondent type

<table>
<thead>
<tr>
<th>FFT Question</th>
<th>The child who went to hospital</th>
<th>The parent or carer of the child who went to hospital</th>
<th>Both child and parent or carer together</th>
</tr>
</thead>
<tbody>
<tr>
<td>Column Valid N</td>
<td>Count</td>
<td>Column Valid N</td>
<td>Count</td>
</tr>
<tr>
<td>I agree a lot</td>
<td>88.0%</td>
<td>147</td>
<td>90.7%</td>
</tr>
<tr>
<td>I agree a bit</td>
<td>7.2%</td>
<td>12</td>
<td>7.8%</td>
</tr>
<tr>
<td>I disagree a bit</td>
<td>.6%</td>
<td>1</td>
<td>.9%</td>
</tr>
<tr>
<td>I disagree a lot</td>
<td>0.0%</td>
<td>0</td>
<td>.3%</td>
</tr>
<tr>
<td>I can’t decide / I don’t know</td>
<td>4.2%</td>
<td>7</td>
<td>.3%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>167</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>