North Thames Children’s Cancer Network

Children’s Cancer Parent and Patient Satisfaction Survey 2014:

Network wide report – thematic analysis

Conducted by: Patient Experience Subgroup of the North Thames Children’s Cancer Network Coordinating Group

Author: Report written by Karen Bravery, Project Nurse, Shared Care Improvement Project, Haematology/Oncology, ICI-LM, Great Ormond Street Hospital

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Background

The Patient Experience Sub Group of the North Thames Children’s Cancer Network Coordinating Group (NTCCNCG) designed a survey in 2013, following a review of similar surveys used by other children’s cancer centres. This network wide survey looked at parent experience and satisfaction with their principle treatment centre (PTC), shared care hospital (known as a ‘Paediatric Oncology Shared Care Unit’ or POSCU) and Children’s Community Nursing (CCN) teams. This survey was distributed to families by staff from the PTC (Great Ormond Street Hospital or University College London Hospital) and by staff from North Thames POSCU’s in September/October 2013. A second network wide survey was undertaken in October 2014.

Methods

Following feedback from the NTCCNCG parent council, the patient experience sub group and PTC/POSCU staff involved in the 2013 survey, some of the questions were revised and amended. See Appendix 1 for details.

The 2014 survey was distributed over a 4 week period, from 06/10/14 until 31/10/14 to families by the PTC. The deadline for survey postal returns from POSCU’s was extended to 26/12/14 to accommodate their request for additional time to distribute and collect surveys.

Families were invited to complete a questionnaire when they attended the PTC as an inpatient, outpatient or day case. At the PTC, the surveys were handed out by the shared care improvement project nurse, the project administrator and the Safari ward administration Team. POSCU nursing and medical leads distributed the survey when families attended the POSCU or invited the families to participate by post or email.

The survey was completed by all families using a paper version or via a SurveyMonkey® link to an online version of the survey. Completed paper versions of the survey were manually entered into the online version (SurveyMonkey®) to facilitate sorting and analysis of the data.

The data were analysed qualitatively by thematic analysis of free text comments made by families. The free text comments for some of the questions were coded as being ‘positive’ or ‘negative’ and an overall percentage of positive and negative comments were calculated per question (Table 1). Some of the questions were excluded from this analysis as the responses would be positive or negative, due to the question asked i.e. what are the best things and the worst things.

All thematic analysis was undertaken by the shared care improvement project team (Karen Bravery, Project Lead Nurse, Rebecca Sweet, Project Clinical Psychologist, Naomi Oldreive, Project Nurse, and Polly Snowdon, Project Administrator).
Results

This report presents the qualitative analysis of the free text comments made by families who completed the survey across the network in 2014. A total of 175 completed surveys were returned and analysed.

The table below gives the overall positive or negative score as a percentage of the total number of comments per question. The table also includes the results of the 2013 and 2014 surveys for comparison.

<table>
<thead>
<tr>
<th>Survey question</th>
<th>2013</th>
<th>2014</th>
<th>Trend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have any further comments about your PTC outpatient clinic?</td>
<td>50%</td>
<td>50%</td>
<td>63% 37% More positive</td>
</tr>
<tr>
<td>Do you have any further comments about the children’s inpatient ward?</td>
<td>52%</td>
<td>48%</td>
<td>20% 80% More negative</td>
</tr>
<tr>
<td>Do you have any further comments about the children’s day care ward?</td>
<td>*</td>
<td>*</td>
<td>40% 60% No comparison</td>
</tr>
<tr>
<td>Do you have any further comments about your local shared care hospital outpatient clinic?</td>
<td>59%</td>
<td>41%</td>
<td>77% 23% More positive</td>
</tr>
<tr>
<td>Do you have any further comments about the children’s inpatient ward at your local shared care hospital?</td>
<td>42%</td>
<td>58%</td>
<td>38% 62% More negative</td>
</tr>
<tr>
<td>Do you have any further comments about your community nursing team?</td>
<td>92%</td>
<td>8%</td>
<td>86% 14% More negative</td>
</tr>
<tr>
<td>Do you have any further comments about ways in which we could address the holistic needs of families?</td>
<td>14%</td>
<td>86%</td>
<td>29% 71% More negative</td>
</tr>
<tr>
<td>Do you have any further comments about communication or information?</td>
<td>27%</td>
<td>73%</td>
<td>13% 88% More negative</td>
</tr>
<tr>
<td>If your child is old enough to express a view, what does he or she think about GOSH/UCLH?</td>
<td>89%</td>
<td>11%</td>
<td>88% 13% More negative</td>
</tr>
<tr>
<td>Do you have any other comments? (GOSH/UCLH)</td>
<td>73%</td>
<td>27%</td>
<td>*    * More negative</td>
</tr>
<tr>
<td>If your child is old enough to express a view, what does he or she think about your local shared care hospital?</td>
<td>69%</td>
<td>31%</td>
<td>74% 26% More positive</td>
</tr>
<tr>
<td>Do you have any other comments? (POSCU)</td>
<td>14%</td>
<td>86%</td>
<td>*    * No comparison</td>
</tr>
</tbody>
</table>

Table 1. A comparison of the overall percentage of positive and negative comments made by families in 2013 and 2014

* The question was not used in both the 2013 and 2014 so a direct comparison is not available

Themes

There were a number of overarching themes that emerged from the free text comments. These were then sub divided further for more information. The Tables below present the themes and associated sub themes. The themes are illustrated throughout with quotes from families.

Total scores were calculated for the number of comments per sub theme. Sub themes with fewer than 28 comments were not included as final sub themes.

The positive themes related to the staff and the care they provide. At a total of 385 comments, these themes generated the greatest number of comments. There were a number of other themes (negative), relating to the environment, facilities, waiting times, communication, education of staff and the provision of play that identified areas for improvement. The total number of comments for these themes was 328.
The final themes and sub themes were:-

1. The staff:
   - Excellent staff (325 comments)
   - Good care provided (60 comments)

2. Environment / Facilities:
   - The quality and timing of the food served (87 comments)
   - Long waiting times (63 comments)
   - Poor environment and facilities (48 comments)

3. Emotional wellbeing of families
   - More play specialists and play facilities needed (28 comments)

4. Communication
   - Poor communication (64 comments)

5. Training and Education
   - More training and education needed at the POSCU (38 comments)

<table>
<thead>
<tr>
<th>Theme: The staff</th>
<th>Sub theme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Excellent staff (325 comments)</strong></td>
<td>Feedback from families about the staff in the PTC, POSCU and Children’s Community Nurse’s was generally very positive. This was echoed in all departments (in-patients, out patients and day care) and across the network</td>
<td>Quotes about PTC staff</td>
</tr>
<tr>
<td></td>
<td>Staff across the network were praised by families for their professionalism, expertise, friendliness, caring nature and for being supportive to families.</td>
<td>“Excellent service from the consultant, doctors and nurses. Very satisfied.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Staff are amazing. Feel like family. Have made me as a parent feel in control and confident.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Members of staff listened and genuinely cared for my child and made him feel very special during and after treatment.”</td>
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<tr>
<td></td>
<td></td>
<td>“Everyone is extremely knowledgeable, caring &amp; reassuring. I always feel like we are in the very safest of hands.”</td>
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<tr>
<td></td>
<td></td>
<td>“Staff, nothing too much trouble, very competent-experts.”</td>
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<tr>
<td></td>
<td></td>
<td>Quotes about POSCU staff</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“We have received lots of support from the hospital staff. Professional care from the doctors and nurses.”</td>
</tr>
</tbody>
</table>
“This ward has good doctors and hardworking nurses. These nurses try their hardest to make the hospital feel like home.”
“Current CNS is very helpful and gets us “in and out” of hospital quickly. Given the months we spend in hospital, we appreciate this!”

“Great CNS nurse always helpful and answering all questions, very professional.”

“The oncology nurse that takes care of my daughter is the best person we’ve met. She is always ready to help us in any situation. She always listens to us and our needs. S loves her”

**Quotes about Children’s Community Nurses**

“Helpful, friendly team, very supportive.”

“They are very caring.”

“Amazing team, they have made my daughter’s treatment much more pleasant.”

“They are always prompt, communicative, reliable & kind.”

“They are very amenable and go out their way to help whenever they can.”

“Always polite, always respectful, always call to arrange a time and most of all always on time. Skills are also exceptional.”

“Fantastic team who answer any concerns and flexibility is great when caring for other children at home.”

<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes</th>
<th>Quotes about care at the PTC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Good care provided (60 comments)</strong></td>
<td>The standard and quality of care across the network was described as excellent and of a high standard.</td>
<td>“Standard of care is excellent”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Can't say enough good things about the staff and the care here. We are very happy.”</td>
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<tr>
<td></td>
<td></td>
<td>“Really excellent care from everyone. The staff all work really hard but always have time to keep patients and parents informed and relaxed. This applies to reception, medical staff, play specialist, hostesses, everyone.”</td>
</tr>
</tbody>
</table>
**Quotes about care at the POSCU**

“Extremely good and personal care. We feel very lucky to be looked after there”

“The hospital is fantastic. The consultant’s, nurse specialists, nurses and everyone are superb. I am very pleased that I chose this hospital and so is my child. I feel extremely confident in the care that is provided for my child and we are treated as individuals. Cannot praise them enough.”

“Excellent care, easy access to ward and CNS”.

<table>
<thead>
<tr>
<th>Theme: Environment/Facilities</th>
<th>Sub theme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The quality and timing of the food served</strong>&lt;br&gt;(87 comments)</td>
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<td></td>
</tr>
<tr>
<td>The quality of the food served at the PTC and the POSCU were seen as areas for improvement.</td>
<td></td>
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<tr>
<td>Quote:</td>
<td></td>
<td></td>
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<tr>
<td><strong>Quotes about the quality of food served at the PTC</strong></td>
<td></td>
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</tr>
<tr>
<td>“Meals poor and not nutritionally balanced. We have to supply food for specific needs (e.g. bananas when more potassium needed). Many other examples.”</td>
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<tr>
<td>“Food is often dry especially chips. Portion sizes are too large- off-putting for a sick child. Would be good to see more &quot;easier to eat&quot; meals like shepherd’s pie, pasta, lasagne.”</td>
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<tr>
<td>“Maybe more &quot;finger foods&quot; on the menu and snack type for when the child is not feeling up to much food.”</td>
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<tr>
<td>“The food isn’t really what I would consider to be healthy food considering the children are fighting cancer.”</td>
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<tr>
<td><strong>Quotes about the quality of food served at the POSCU</strong></td>
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<tr>
<td>“The only negative note is the food which is distasteful.”</td>
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<tr>
<td>“My child is on a restrictive MEWS diet and several times he has been fed wheat. The cook has told me the writing is too small on the ingredients packaging for her to see his restrictions.”</td>
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<tr>
<td>“The food is atrocious!! More effort should be made to provide well cooked, healthy meals for unwell children.”</td>
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</tbody>
</table>
There were several comments that the evening meal was served too early and too close to lunch at the PTC.

<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes about the timing of the food served at the PTC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long waiting times (63 comments) Waiting times at the PTC</td>
<td>“Meals are not nice. My son would not eat.”</td>
</tr>
<tr>
<td></td>
<td>“There were problems with the food: families being fed over and above patients.”</td>
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<tr>
<td></td>
<td>“The meal times are good, but not varied enough for children who are in hospital for a long time. Menu is new and good, but it does get a bit boring for the child after a while.”</td>
</tr>
<tr>
<td></td>
<td>“No food available for coeliac.”</td>
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<tr>
<td></td>
<td>“I feel that healthier options of food could be served.”</td>
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<tr>
<td></td>
<td>“Lunch and specially dinner are too early (16.30 dinner). By the time she has them the food is cold and impossible to be eaten.”</td>
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<tr>
<td></td>
<td>“Oncology children need nutrition. They need to eat to eat or they will lose weight and need a feeding device. The food is horrible, dry and I wouldn’t feed it to a pet! The timing is ridiculous 1pm lunch, 4pm dinner who eats that quick.”</td>
</tr>
<tr>
<td></td>
<td>“Food of low standard. Evening meal served too early 4.30pm!”</td>
</tr>
</tbody>
</table>

There were comments from families about waiting times for procedures and treatments experienced at the PTC. Some families felt they were not informed of the reason for the delays they encountered.

<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes about waiting times at the PTC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long waiting times (63 comments) Waiting times at the PTC</td>
<td>“Waiting time for chemotherapy in the outpatient ward is very long especially when child is on fasting from last night.”</td>
</tr>
<tr>
<td></td>
<td>“Waiting, sometimes 2/3 hours before day procedure-difficult when children are fasting. An allocated time slot to arrive would be more beneficial.”</td>
</tr>
<tr>
<td></td>
<td>“My only comment relates to timings - it’s not entirely clear when you will be seen and sometimes takes longer than expected. The nurses are all extremely busy - it would be great if the receptionists (who aren’t always that friendly) were more on top of when you are likely to be seen.”</td>
</tr>
<tr>
<td></td>
<td>“On our first visit, there were long periods of time when no-one came and told us why there were delays in the treatment. It was very stressful. This has much improve- thank-you.”</td>
</tr>
</tbody>
</table>
There were fewer comments about waiting at the POSCU

“Speed up waiting times for treatment.”
“Very long wait times- rarely under 2 hours. Visits even for a simple injection take a full day.”
“A simple grid. When a patient arrives, it needs to be marked out all the treatment s/he needs- so that they are accessed in time for their surgery slot, and the meds they need are ordered up from pharmacy in time and long waits and overcrowding are minimised.”

Quotes about waiting times at the POSCU

“Waiting too long”
“Long wait times sometimes for A &E situations”
“Sometimes long wait for medicine from pharmacy”
“Waiting around for doctors when an inpatient”
“Waiting for a bed on admission”

<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor environment and facilities (48 comments)</td>
<td>Quotes about the environment and facilities at the PTC</td>
</tr>
</tbody>
</table>
| At the PTC some families felt that the wards were too hot in the summer and too crowded | “Ward has no air con and lots of windows so sunny days are like a greenhouse. Limited number of windows open.”
“It was not ok with us to spend up to 8 hours on crowded wards when our son was neutropenic.”
“Clean the rooms! The drawers are filthy! and the bath.”
“Kitchen for parents is stiflingly hot.”
“Lovely and warm in winter, just too hot in summer.”
“It’s too hot in the bays.” |
| Quotes about the environment and facilities at the POSCU | “There are bugs in the bathroom and the toilets are unhygienic and the floor has lots of stains.”
“Facilities need to be updated really, but clean and ok.”
“The parents beds are chairs and very uncomfortable.” |
Some families felt that the facilities could be improved or updated at the POSCU

<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>More play specialists and play facilities needed at the PTC and the POSCU (28 comments)</strong></td>
<td><strong>Quotes about Play at the PTC</strong></td>
</tr>
<tr>
<td>Some families felt that access to play specialists, activities and play facilities could be improved</td>
<td>“During our last visit, most of the toys with batteries were not working. This became a little frustrating, especially for our son, as the toys are such a good distraction and source of fun.”</td>
</tr>
<tr>
<td></td>
<td>“Provide more play staff and TV/DVD entertainment toys.”</td>
</tr>
<tr>
<td></td>
<td>“Not enough activities”</td>
</tr>
<tr>
<td></td>
<td>“It would be great if more play specialists could be available.”</td>
</tr>
<tr>
<td></td>
<td><strong>Quotes about play at the POSCU</strong></td>
</tr>
<tr>
<td></td>
<td>“Maybe provide Wi-Fi, have movies or add on cartoon channels to distract kids.”</td>
</tr>
<tr>
<td></td>
<td>“More toys and play nurses needed during waiting times.”</td>
</tr>
<tr>
<td></td>
<td>“TV does not work in all rooms.”</td>
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<tr>
<td></td>
<td>“All good. But would be great if the play room wasn’t all locked up at weekends which is when we tend to be in (I understand it relates to budgets and play specialists not being around at weekends).”</td>
</tr>
<tr>
<td></td>
<td>“The fact that the playroom is shut on the weekends.”</td>
</tr>
<tr>
<td></td>
<td>“Employ play specialists at weekends.”</td>
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</tbody>
</table>

No access to play at the weekend was highlighted as a concern for families
<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor communication (64 comments)</td>
<td>“Communication between PTC and local hospital, which we attend for injections and blood results, is poor.”</td>
</tr>
<tr>
<td>Communication between the PTC and the POSCU was described by some families as an area that could be improved. There were also some comments about poor communication with families</td>
<td>“Communication gaps between departments and hospitals”</td>
</tr>
<tr>
<td></td>
<td>“Communication is disgusting. Example- my son had an emergency tumour removed we were released too early and I told the CCN team we been home after 48hrs as they hadn’t contacted us, they didn’t even know we had been admitted.”</td>
</tr>
<tr>
<td></td>
<td>“Communication/ updates with parents and processes.”</td>
</tr>
<tr>
<td></td>
<td>“No communication. No explanations when things go wrong! No follow up team. My son was diagnosed in July 2014, I met a keyworker briefly in Sept 2014!”</td>
</tr>
<tr>
<td></td>
<td>“Better communication, a keyworker available that you can phone- when has already met you in person and can assist with questions/co-ordination of treatment.”</td>
</tr>
<tr>
<td></td>
<td>“I would love to replace the many letters from GOSH- particularly those regarding appointments. We do get text messages from the automated system which is helpful but am sure the letters could be sent by email?”</td>
</tr>
<tr>
<td></td>
<td>“Communication with GOSH is a big issue. The whole hospital needs to be more joined up.”</td>
</tr>
<tr>
<td></td>
<td>“Communication, the staff need to be more friendly and supportive to family.”</td>
</tr>
<tr>
<td></td>
<td>“Ensure patients and families always know why there are delays.”</td>
</tr>
</tbody>
</table>
### Theme: Training and Education

<table>
<thead>
<tr>
<th>Sub theme</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>More training and education needed at the POSCU (38 comments)</td>
<td>“Numerous issues with some of the medical advice given by random ward doctors- night time shifts et. Sending her home when she had temp of 38.3-38.4, sending her home with no antibiotics when she was neutropenic and had a chest infection. Probably 4-5 significant issues like this.”</td>
</tr>
<tr>
<td></td>
<td>“A few nurses know us and my child’s illness. We have had numerous doctors and nurses who told us they never cared for a child with leukaemia. It shows with their lack of knowledge and hygiene.”</td>
</tr>
<tr>
<td></td>
<td>“Lack of experienced medical team”</td>
</tr>
<tr>
<td></td>
<td>“Knowledge and expertise isn’t widely spread amongst staff when staying on the ward.”</td>
</tr>
<tr>
<td></td>
<td>“When you have a new doctor that doesn’t know our history, they can be dismissive.”</td>
</tr>
<tr>
<td></td>
<td>“Lack of expertise when our consultant is not available.”</td>
</tr>
<tr>
<td></td>
<td>“If the main/lead nurse is not there they don’t seem to know what they are doing.”</td>
</tr>
<tr>
<td></td>
<td>“More staff training on ALL and other cancers.”</td>
</tr>
<tr>
<td></td>
<td>“Staff training, compared to PTC, POSCU are under qualified and you feel like you are left in the hands of God.”</td>
</tr>
<tr>
<td></td>
<td>“Doctors- very defensive about their lack of knowledge. Slow to treat because need to contact GOSH. Doctors have no empathy- we have lived in hospital for months!”</td>
</tr>
</tbody>
</table>
Appendix 1 Revisions made to the 2013 survey questionnaire

Minor revisions were made to some questions that were frequently skipped by parents completing the survey in 2013.

All of the ‘Holistic Needs Assessment’ related questions were combined into one section and some of these questions were deleted to make this section clearer and shorter. This was requested by the Parent Council and Patient Experience Sub-group Lead (Zoe Berger – ZB).

Separate sections were created for the inpatient ward and day care ward at the PTC. This was requested by the PTC day care sister, UCLH matron and the service manager (GOSH). For the 2013 survey, there was only one set of questions that asked for feedback about the inpatient and day care wards at the PTC. This meant it was difficult to identify where problems were occurring and formulate action plans as parents scored both wards in one set of questions.

A new question was added: “If you had a concern about your child or their treatment who would you contact?” The option was given to name a contact at the UCLH/GOSH and the POSCU. This was requested by the GOSH Haematology ANP in order to see if there is a difference in who families view as their main contact or if they view their CNS or the key worker as the main contact.

A new line was added to the question asking parents what information they had received in to ask if they had received information about your child’s Multi-Disciplinary Team. This was requested by the service manager at GOSH as this is needed for peer review (Cancer measure 14-7B-211 – Patient feedback).

A new section was added to the end of the survey with 2 new questions requested by the Parent Council/Patient Experience Sub-group to obtain feedback on parent’s experiences of completing the survey.

Information about the Parent Council was added at the end of the survey to raise awareness amongst parents about the parent council and to aid recruitment to the group. This was requested by the Parent Council.