**Appendix**

**Supplementary methods**

The survey was commissioned by the Care Quality Commission and developed and coordinated by Picker Institute Europe.[20] Age-appropriate designs and illustrations were used on the child and young person tools, and the questions focus on areas of care that are most important to this population. For example, the version for younger children asked whether hospital staff played with them, whereas the version for older children asked if there were enough things for someone of their age to do on the ward. Two reminder mailings were sent to non-responders, with 2-3 weeks between mailings. All families were given the chance to opt out of the survey via a dissent process prior to the survey commencing. Each NHS Trust sampled between 300 and 850 patients depending on their throughput.

The overall response rate for the survey was 27%. However, this study only looked at two out of the three survey versions. The response rates for those are 29% for 8-11s and 30% for 12-15s. The response was rather lower for the (excluded) 0-7s = 26%, which brings the overall rate down. Where the parent section was completed, the CYP section was completed in 98% of cases.

**Appendix Table A1**

**Questions used to compare parents and their children’s self-reports about the same inpatient episode. Children and Young People’s Inpatient Survey, England, 2014.**

|  |  |  |
| --- | --- | --- |
| **Label** | **Children and Young People section – question and dichotomised response** | **Parent section – question and dichotomised response** |
| Presence of pain | Did your condition ever cause you pain when you were in hospital?  (Yes vs. no) | Did your child's condition cause them any pain when they were in hospital?  (Yes vs. no) |
| Pain relief | Do you think the hospital staff did everything they could to help your pain?  (Yes vs. no) | Do you think hospital staff did everything they could to help ease your child's pain?  (Yes vs. no) |
| Overall experience | Overall experience  (0-8/10 vs. 9-10/10) | Overall experience  (0-8/10 vs. 9-10/10) |
| Involvement in decisions | Were you involved in decisions about your care and treatment?  (Yes vs. sort of/no) | Were you encouraged to be involved in decisions about your child's care and treatment?  (Yes definitely, vs. yes to some extent/no). |
| Communication on arrival | When you first arrived at hospital, did people working at the hospital tell you what was going to happen to you while you were there?  (Yes vs. sort of/no) | Did hospital staff tell you what was going to happen to your child while they were in hospital?  (Yes definitely, vs. yes to some extent/no). |
| Communication about care and treatment | Did hospital staff talk to you about how they were going to care for you, in a way that you could understand?  (Yes vs. sort of/no) | Did members of staff treating your child give you information about their care and treatment in a way that you could understand?  (Yes definitely, vs. yes to some extent/no). |
| Communication before operation/  procedure | Before the operation or procedure, did hospital staff tell you what would be done?  (Yes vs. sort of/no) | Before the operation or procedure, did a member of staff explain to you what would be done during the operation or procedure?  (Yes definitely, vs. yes to some extent/no). |
| Communication after operation/  procedure | Afterwards, did someone from the hospital explain to you how the operation or procedure had gone in a way you could understand?  (Yes vs. sort of/no) | After the operation or procedure, did someone explain to you how the operation or procedure had gone in a way you could understand?  (Yes definitely, vs. yes to some extent/no). |
| Discharge communication | Did a member of staff tell you what would happen after you left hospital?  (Yes vs. sort of/no) | Did a member of staff tell you what would happen next after your child left hospital?  (Yes definitely, vs. yes to some extent/no). |
| Advice on post-discharge care | Did a member of staff give you advice on how to look after yourself after you went home?  (Yes vs. sort of/no) | Did a member of staff give you advice about caring for your child after you went home?  (Yes definitely, vs. yes to some extent/no). |

Notes

1. This table presents the wording of questions and responses used in the second set of analyses that are described in the methods sections (Analysis of CYP-parent dyads)
2. For the purposes of assessing hospital performance, pain relief is the primary measure of interest; presence of pain is used as a filter question to identify patients for whom the pain relief question is relevant. Both questions are included in these analyses, as accurate answers to both are necessary to assess performance on pain relief and, in both cases, there is potential for the views of CYP and their parents to differ.
3. Some questions were not included or were worded differently in the versions of the survey given to children (8-11 years) and young people (12-15 years). This results in significantly lower N values for some questions.

**Appendix Table A2**

**Questions used to compare responses to the Children and Young People section by CYP themselves, their parents/carers and joint responses. Children and Young People’s Inpatient Survey, England, 2014.**

|  |
| --- |
| **Children and Young People section – question and dichotomised response** |
| Did hospital staff play with you or do any activities with you while you were in hospital?  (Yes vs. soft of/no) |
| Were there enough things for someone of your age to do on the ward?  (Yes vs. sort of/no) |
| Did you like the hospital food  (Yes vs. sort of/no) |
| Did hospital staff talk to you about how they were going to care for you, in a way that you could understand?  (Yes vs. sometimes/no) |
| Were you involved in decisions about your care  (Yes vs. a little bit/no) |
| If you had any worries, did someone at the hospital talk with you about them?  (Yes vs. sort of/no) |
| Did staff talk to each other about you as if you weren't there?  (Yes, definitely vs. sort of/no) |
| Were you given enough privacy when you were receiving care and treatment?  (Yes, always vs. yes, sometimes/no) |
| Did your condition ever cause you pain when you were in hospital?  (Yes vs. no) |
| Do you think the hospital staff did everything they could to help your pain?  (Yes vs. sort of/no) |
| Do you feel that the people looking after you listened to you?  (Yes, always vs. yes, sometimes/no) |
| Do you feel that the people looking after you were friendly?  (Yes, always vs. yes, sometimes/no) |
| Overall experience  (0-8 vs. 9-10/10) |

Notes:

1. This table presents the wording of questions and responses used in the third set of analyses that are described in the methods section (Analysis of differences between parent, CYP, and joint responses to the CYP section)

**Appendix Table B**

**Proportion of positive responses to selected questions in the CYP section of the English Children and Young People’s Inpatient and Day Case Survey 2014, by respondent group**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **Parent/carer** | | **CYP** | | **Joint** | | **Total** |
|  |  | **%** | **N** | **%** | **N** | **%** | **N** | **N** |
| Did hospital staff play with you or do any activities with you while you were in hospital? Ages 8-11 (%) B2 |  | 26 | 270 | 20 | 746 | 27 | 461 | 1477 |
| Were there enough things for someone of your age to do on the ward? (12-15) B3 |  | 29 | 269 | 22 | 1597 | 29 | 639 | 2505 |
| Did you like the hospital food? B4 |  | 40 | 527 | 45 | 2633 | 44 | 1253 | 4413 |
| Did hospital staff talk to you about how they were going to care for you, in a way that you could understand? C1 |  | 80 | 775 | 81 | 3372 | 84 | 1713 | 5860 |
| If you had any worries, did someone at the hospital talk with you about them? CYP C3 |  | 72 | 621 | 74 | 2492 | 78 | 1340 | 4453 |
| Did staff talk to each other about you as if you weren't there? C4 |  | 10 | 267 | 6 | 1579 | 7 | 650 | 2496 |
| Were you given enough privacy when you were receiving care and treatment? C5 |  | 84 | 790 | 79 | 3502 | 84 | 1755 | 6047 |
| Did your condition ever cause you pain when you were in hospital? D1 |  | 57 | 784 | 66 | 3486 | 63 | 1761 | 6031 |
| Do you think the hospital staff did everything they could to help your pain? D2 |  | 81 | 400 | 80 | 2058 | 83 | 945 | 3403 |
| Do you feel that the people looking after you listened to you? G1 |  | 75 | 788 | 79 | 3501 | 79 | 1771 | 6060 |
| Do you feel that the people looking after you were friendly? G2 |  | 85 | 796 | 89 | 3513 | 88 | 1775 | 6084 |
| Overall… CYP G3 |  | 38 | 778 | 30 | 3440 | 38 | 1724 | 5942 |

Notes

1. The CYP section of the survey was aimed at CYP, but could be answered by parents/carers (N=849), CYP (N=3592), or jointly (N=1763).
2. N values differ, as questions on pain relief and communication before/after operation/procedure were not applicable to all patients and questions on involvement, discharge communication and advice on post-discharge care only apply to young people aged 12-15 years (as they were worded differently in the surveys for children 8-11 years).
3. N values are larger than in Table 2, as Table 2 excludes participants for whom any covariate data is missing.

**Appendix Table C**

**Overall care ratings in children and young people (CYP) section of the survey, by main person who answered the question. CYP Inpatient Survey, England, 2014.**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Main person who answered the question | | | | | |  | |
| Child/young person | | Parent/carer | | Young person and parent/carer together | | Total | |
| 0 (I had a very poor experience) | 8 | 0% | 9 | 1% | 13 | 1% | 30 | 0% |
| 1 | 12 | 0% | 11 | 1% | 8 | 0% | 31 | 1% |
| 2 | 17 | 0% | 6 | 1% | 4 | 0% | 27 | 0% |
| 3 | 41 | 1% | 17 | 2% | 18 | 1% | 76 | 1% |
| 4 | 46 | 1% | 9 | 1% | 18 | 1% | 73 | 1% |
| 5 | 158 | 5% | 37 | 5% | 80 | 5% | 274 | 5% |
| 6 | 168 | 5% | 30 | 4% | 69 | 4% | 267 | 4% |
| 7 | 380 | 11% | 68 | 9% | 178 | 10% | 625 | 11% |
| 8 | 717 | 21% | 164 | 21% | 322 | 19% | 1203 | 20% |
| 9 | 870 | 25% | 134 | 17% | 360 | 21% | 1364 | 23% |
| 10 (I had a very good experience) | 1024 | 30% | 293 | 38% | 656 | 38% | 1973 | 33% |
| Number of respondents | 3440 | 100% | 778 | 100% | 1724 | 100% | 5942 | 100% |

**Appendix Table D. Concordance between exact overall care ratings by children & young people (CYP) and parents. CYP Inpatient Survey, England, 2014.**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **Overall care rating (child/young person)** | | | | | | | | | | | Total |
|  | | **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| **Overall care rating (parent/carer)** | **0** | 2 | 4 | 1 | 1 | 0 | 1 | 0 | 0 | 1 | 0 | 1 | 11 |
| **1** | 0 | 3 | 7 | 4 | 2 | 1 | 0 | 0 | 0 | 1 | 0 | 18 |
| **2** | 1 | 2 | 4 | 4 | 3 | 2 | 0 | 1 | 0 | 1 | 0 | 18 |
| **3** | 0 | 1 | 2 | 7 | 4 | 3 | 1 | 1 | 2 | 0 | 0 | 21 |
| **4** | 0 | 0 | 1 | 7 | 16 | 10 | 7 | 2 | 3 | 1 | 1 | 48 |
| **5** | 0 | 0 | 2 | 5 | 6 | 44 | 12 | 13 | 10 | 5 | 6 | 103 |
| **6** | 2 | 2 | 1 | 2 | 8 | 32 | 33 | 34 | 15 | 11 | 4 | 144 |
| **7** | 1 | 0 | 1 | 3 | 2 | 24 | 29 | 100 | 86 | 35 | 12 | 293 |
| **8** | 1 | 0 | 0 | 1 | 3 | 23 | 32 | 110 | 294 | 173 | 89 | 726 |
| **9** | 0 | 0 | 0 | 1 | 3 | 11 | 20 | 68 | 205 | 433 | 180 | 921 |
| **10** | 1 | 1 | 0 | 4 | 0 | 8 | 15 | 34 | 86 | 208 | 734 | 1091 |
| **Total** | | 8 | 13 | 19 | 39 | 47 | 159 | 149 | 363 | 702 | 868 | 1027 | 3394 |

Notes:

Responses by CYP, and their parents were the same in 49·2% of cases; a further 32·9% were within one point of each other. In the remaining 609 (17·9%) cases, responses differed by at least 2 points (range 2-10). Young people were less positive than their parents in 28·6% of dyads.