Patient Experience Questionnaire

Summary of results from 2015/2016 for

The Ipswich Hospital NHS Trust

Donna Coe, Patient and Public Involvement Manager
Patient Experience Questionnaire
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The Ipswich Hospital NHS Trust

The NIHR Clinical research Network: Eastern carried out a Patient Experience Questionnaire for the second year running. There were two versions of the questionnaire, one aimed at adults (Appendix A) and one aimed at children and their carers (Appendix B). This report is divided into two sections, Part A sets out the results of the Adults and Part B sets out the results of the Children’s questionnaires. The questionnaire ran from November 2015 to February 2016.

The purpose of the questionnaire was to capture the patient experience of research in multiple settings, organisations and research studies across the Eastern region. The information collected will be used to continuously improve the patient experience.

This report summarises the results of the Patient Experience Questionnaire 2015/16 for the Ipswich Hospital NHS Trust only. The results from the whole Eastern Region are in a separate report.

1. Participation rates

Of the 19 Trusts located in the Eastern Region, 12 collected data using the Patient Experience Questionnaire and a total of 391 respondents completed a questionnaire. The Ipswich Hospital NHS Trust collected in 70 completed questionnaires. Of these, 35 were adult questionnaires, the results of which can be found in Part A of this report, and 35 were children’s questionnaires, the results for which can be found in Part B.
2. Specialty Areas

The questionnaire asked for the respondent to identify which Specialty Area the research came under. A total of 7 out of a possible 30 Specialty Groups were represented in the questionnaire results for the Ipswich Hospital NHS Trust.

Out of the 70 questionnaires completed at the Ipswich Hospital NHS Trust, 35 were in the Specialty Area of Children, 18 were for Cancer, 7 were for Renal Disorders, 3 were Dermatology, 3 were for Musculoskeletal Disorders, 3 were for Neurological Disorders and 1 was for Diabetes.

3. Part A - Adults

A copy of the adult’s questionnaire can be found in Appendix A of this report.

3.1 Understanding information

Did you understand the information provided?

When asked “did you understand the information provided?” the majority of respondents were able to “totally” understand the information provided by the research staff (66%).
However, a number of respondents weren’t completely able to understand the information provided with 26% answering that they “mostly” understood and 6% saying that they only “partly” understood.

On the whole, most of the respondents (66%) said they “totally” understood, when asked “did you feel that you understood what you were consenting too?”. A smaller number of respondents didn’t completely understand what they were consenting to, with 29% answering that they “mostly” understood the information provided at all.
Were your questions answered in a way you could understood?

When asked “were your questions answered in a way you understood?” most respondents (77%) felt their questions were, with only a small number stating that they could “mostly” understand (17%).

Out of the 35 adult participants, 6 left comments which were mostly positive about their level of understanding. Here are a sample of the comments:

“Any questions I asked, were explained to me in detail”

“Clear answers which I could understand”

“If I had any queries, they were explained to me”

“Such an enormous amount of information to digest following diagnosis - I felt more questions may arise as the treatment commences”
3.2 Contact

**Did you feel there was enough contact between you and the research staff?**

When asked, “Did you feel there was enough contact between you and the research staff?” the majority of respondents (83%) felt there was and 14% felt there was “mostly” enough contact with the research staff suggesting these respondents would’ve preferred a little more.

![Bar chart showing contact satisfaction]

3.3 Difficulties participating

**Did you experience any problems getting to the research appointments, e.g. parking?**

The result was very divided when asked “did you experience any problems getting to the research appointments, e.g. parking?”. Over half of the respondents (57%) stated that they didn’t experience any problems and 9% felt that it wasn’t relevant. There were however a significant number of respondents who did have difficulties to varying levels, with 14% “partly” having problems, 6% “mostly” having problems and 14% “totally” experiencing problems.
Was the time and date of your appointment suitable, and appropriate?

Most respondents (71%) were totally satisfied and some (14%) were “mostly” satisfied when asked “was the time and date of your appointment suitable, and appropriate?”. However a small number of respondents did not find the time and date suitable with 9% saying it was only “partly” suitable.
Is payment for (travel or time) a factor in your decision to assist with research?

When asked “is payment for (travel or time) a factor in your decision to assist with research?” the majority of respondents (54%) said no, not at all or felt it wasn’t relevant (31%). However a small number of respondents (11%) felt that it was “partly” a factor in their decision when deciding to take part in research.

3.4 Finding out more information

If you were interested, do you know how to find out the results of the study?

The respondents held a mixed view, when asked “if you were interested, do you know how to find out the results of the study?”. A third of respondents (31%) felt they had no idea how to access this information, should they wish to find out, whilst 20% felt they “partly” knew how to find out the results and 26% “mostly” knew. Only 14% of respondents were “totally” confident they knew how to find out more.
3.5 Promoting research

**Would you recommend taking part in this research study to other eligible people?**

Almost all of the respondents (74%) said they would, when asked “would you recommend taking part in this research study to other eligible people?”. A much smaller number appeared to have some level of reservations, with 14% stating they would “mostly” recommend taking part and 6% saying they would “partly” recommend taking part.
How did you find out about this study?

The participants were asked “how did you find out about this study?”. The vast majority found out about the research through the clinic or hospital which they attended, through a member of staff approaching them e.g. doctor, consultant, nurse or a member of the research team. A number of other sources were identified, these included the internet or through a leaflet or poster.

When asked how they would like to find out about other studies, a mixture of genres were given as options, some respondents gave more than one option. These included face to face, through a website, by email, by letter and by telephone. (Question 11)

3.6 Why take part?

Tell us why you agreed to take part in the study?

Respondents were asked to “tell us why you agreed to take part in the study”. Respondents provided a variety of reasons, the main ones being to help find new treatments for patients and to make life better for others in the future.

Respondents cited reasons such as:

- To help with research
- Find new treatments and a cure
- Make life better for other patients
- Improve life for myself
- To improve the NHS
- To learn about my condition

Some typical responses included:

“Aid future research and possible cure”

“Because I believed I would be receiving the best treatment and I fully support the drive to learn more about cancer and therefore improve treatment and understanding”

“I hoped it would prolong my life and if not be a benefit to others”
“Staff member was enthusiastic about its value, especially for spontaneity”

“Wish to get better I felt confident in the people providing the information”

### 3.7 Improving the experience

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<tr>
<th>What would have improved your experience of taking part in this study?</th>
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When asked “what would have improved your experience of taking part in this study?”, the majority of respondents felt that being a part of a research trial had been a good experience and they felt that nothing could be improved. There were however a number of things suggested to improve the experience for participants.

Some of the themes running through these suggestions include:

- More contact with the Research Team
- Easier parking
- More feedback
- Smaller tablets

### 4. Part B - Children

A copy of the children’s questionnaire can be found in Appendix B of this report.

### 4.1 Understanding information

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<th>Did you understand the information provided?</th>
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When asked “did you understand the information provided?” the majority of respondents were able to “totally” understand the information provided by the research staff (66%). However, a number of respondents weren’t completely able to understand the information provided with 29% answering that they “mostly” understood and 6% saying that they only “partly” understood.
Did you feel that you understood what you were consenting too?

On the whole, most of the respondents (86%) said they “totally” understood, when asked “did you feel that you understood what you were consenting too?”. A smaller number of respondents didn’t completely understand what they were consenting to, with 11% answering that they “mostly” understood and 3% saying they didn’t understand the information provided at all.
Were your questions answered in a way you could understood?

When asked “were your questions answered in a way you understood?” the majority of respondents (89%) felt their questions were, with only a small number stating that they could “mostly” understand (11%).

There were 2 comments left for this question:

“Any questions I asked, were explained to me in detail”

“Good job lads”

Did you feel you were told enough during the study?

When asked, “Do you feel you were told enough during the study?” the majority of respondents (83%) felt they were, however, 14% felt they were “mostly” told enough and 3% felt they were “partly” told enough. This suggests that 17% of participants would have like to have been told more during the study.
4.2 Difficulties participating

Did you miss any school because of your research appointment?

The result was divided when asked “did you miss any school because of your research appointment?”. Just under half of the respondents (46%) stated that they didn’t miss any school. However, 17% did miss school because of their research appointment and 31% “partly” missed school to attend their appointments.
Were you happy with the time and date of your research appointment?

Most respondents (63%) were totally happy and some (23%) were “mostly” happy when asked “were you happy with the time and date of your research appointment?”. However a small number of respondents were not completely happy with the time and date with 9% saying were “partly” happy and 3% saying they were not happy at all.

Is getting a certificate for taking part important to you?

When asked “is getting a certificate for taking part important to you?” almost three quarters of respondents (74%) said no, getting a certificate was not important to them. However a smaller number of respondents felt that it was important to get a certificate, with 9% saying it was “totally” important, 6% saying it was “mostly” important and 3% saying it was “partly” important to them.
4.3 Finding out more information

If you were interested, do you know how to find out the results of the study?

The respondents held a mixed view, when asked “if you were interested, do you know how to find out the results of the study?”. A third of respondents (34%) felt they had no idea how to access this information, should they wish to find out, whilst 20% felt they “partly” knew how to find out the results and 20% “mostly” knew. Only 23% of respondents were “totally” confident they knew how to find out more.
4.4 Promoting research

Would you tell/encourage other people to take part in research?

The majority (86%) of respondents said they would, when asked “would you tell/encourage other people to take part in research?”. A smaller number appeared to have some level of reservations, with 6% stating they would “mostly” recommend taking part and 6% saying they would “partly” recommend taking part. Nobody said that they would not recommend taking part in research at all.
**How did you find out about this study?**

The participants were asked “how did you find out about this study?”. The vast majority found out about the research through the clinic or hospital which they attended, through a member of staff (e.g. doctor, consultant, nurse or a member of the research team) approaching them face to face, by telephone or by letter. A few respondents found out through a leaflet.

When asked how they would like to find out about other studies, a mixture of genres were given as options, some respondents gave more than one option. These included face to face, through a website, by email, by letter and by telephone. (Question 11)

Most participants preferred to be contacted through Email, letter or face to face. Others preferred a website, a poster or a leaflet or had no preference.

**4.5 Why take part?**

**Tell us why you agreed to take part in the study?**

Respondents were asked to “tell us why you agreed to take part in the study”. Participants cited a variety of reasons, the main ones being to help find new treatments for patients and to make life better for others in the future.

The reasons for taking part in the study included:

- To find new treatments and a cure
- To make life better for other patients
- To improve life for my child
- To learn about my condition

Some typical responses:

“Chance to help my child and others in the future”

“My child was very eager to take part in the study as she feels she would like to help”
“Child was happy to take part and hopeful research will lead to better control/cure in future”

“To hopefully find a cure or better treatment”

“I feel the more research there is, the easier it will be for my child to live with diabetes”

“Because I like learning things that happen to me”

4.6 Improving the experience

What would have improved your experience of taking part in this study?

When asked “what would have improved your experience of taking part in this study?” the majority of respondents felt that being a part of a research trial had been a good experience and they felt that nothing could be improved. There were however a few suggestions made to improve the experience for participants:

● Child friendly information

“To be given information in a book or pictures so the children can understand the need for research”

● Less procedures

“Less blood being taken”

● Separate study appointments

“More study appointment not integrated with clinic”
5. Other comments

Out of the 70 respondents, 14 left additional comments in a space at the end of the questionnaire. The majority of the comments were in appreciation of the research and the research staff. Here are some of the comments:

“I have felt very proud to have taken part”

“I have always felt able to contact the research team when I have a query and they have always given me time and information”

“Thanks for the opportunity, it was worthwhile”

“Very helpful staff, always ready to help”

“Very pleased with information provided throughout. Joined up working between departments, care of staff and presence of Clinical Trials Practitioner”

“Very positive experience with no pressure, so also fun”

Some comments suggested areas where improvements could be made:

“I think the questionnaire that we received after consultation to be very vague. What's a long walk? What's a short walk? Etc”

“It was ideal to have a research appointment at the same time as the general appointment, although we would prefer an after school appointment. We were always advised when and what would be done and reasons for this. My child was always asked about his continued consent. We did have to miss some.”

“Our child was given written information saying not to eat from 10 pm the night before the final test. This information was totally incorrect according to the researcher at GOSH who did the test”

6. Sharing your story

Respondents were asked if they would like to share their story,

4 of the respondents provided their contact details. These people are being followed up by our PPI Administrator who will record an in-depth telephone interview with them about their experience.
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7. Conclusion

- This year 12 of the 19 trusts in the Eastern region collected 391 completed patient experience questionnaires, which is a huge increase on last year when 142 were completed (excluding Primary Care). We will be working to improve the participation of Trusts for the next survey.
- A wider number of Specialty Groups were involved this year with 19 of the 30 Specialty Groups being represented, compared to 14 last year.
- Primary Care is not included in this report as 2 major studies are still running. These findings will be analysed later in the year. Last year 364 questionnaires were completed in Primary Care.
- It is clear from the findings that the majority of respondents, both adults and children, understood the information provided to them and felt that they understood what they were consenting to. Only a small percentage found difficulty in this area, and it should be noted that 2% of children and their carers did not understand what they were consenting to at all. The majority of the comments left by both adults and children with regard the level of understanding were very positive.
- Whilst the majority of adult respondents felt that there was enough contact between them and the research staff, there was still a small element who felt more was needed. This is further reinforced in the comments section with a small number of participants highlighting that more contact would improve the experience.
- Most adult respondents felt that the time and date of the appointment was suitable. However, whilst slightly over half the respondents did not have any problems getting to the research appointment, just under half experienced some level of difficulty. Parking and distance to the appointment was cited a number of times, in the comments sections, as causing a difficulty.
- Over half of the children and their carers felt that the time and date of their appointment was suitable, however just under half experienced some level of difficulty with 2% not at all happy.
- Over half the adult respondents stated that payment (for travel or time) did not play a factor in their decision to assist with research, but it is clear that for a small proportion, payment is necessary in order for them to participate. It is important to ensure that payment is available so that all eligible members of the public are given the opportunity to take part.
- Whilst nearly two thirds of children questioned did not think it was important to get a certificate, one third of children still think it is important.
- It is clear from the results of the questionnaire that there is work to be done in making sure all participants are given clear instructions on how to access the results.
of the trial they have taken part in. This is further reinforced by the number of respondents making a comment about wanting to find out the results.

● The majority of respondents found out about the research from the staff at the hospital or clinic which they attended. They have stated that they prefer to find out about research through email, letter or face to face, although some still prefer to use the internet or like to see posters or flyers. This would suggest that we should include all of these forms of communication to promote research and when looking to recruit to research trials.

● The questionnaire results show that for most people who take part in research it is a very positive experience and most would recommend it to others. The majority of respondents left a reason for why they took part, and these reasons were almost completely positive. The main themes were to find new treatments or to make life better for others and to improve the NHS.

● A number of participants (16%) were willing to provide their contact details so that we can follow them up with an in-depth telephone interview about their experience.

● This is the second Patient Experience Questionnaire in the CRN:Eastern region, and will continue to be sent out annually. Plans have been made to send out the questionnaire for 2016/17 in September rather than the end of the year, to assist with participation levels. The running time of the Patient Experience Questionnaire will be increased from 6 weeks to 8 weeks, to ensure all Trusts are able to participate.

● The 2016/17 questionnaire will be standardised in line with the National CRN Patient Experience Questionnaire, which should be available for use very soon.
Appendix A

Your experience of taking part in research

Thank you for taking part in this study. Your contribution is important and this optional questionnaire has been designed by the Clinical Research Network to find out what you think and feel about being involved in research. It does not form part of the study itself. You don’t have to fill it in, but your feedback will help us to make future studies a better experience for people that take part.

Your responses will be treated anonymously and individual responses will not be identifiable in future reports or publications of results.

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<thead>
<tr>
<th>1. Did you understand the information provided?</th>
<th>Yes, totally</th>
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<td>2. Did you feel that you understood what you were consenting to?</td>
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<td>3. Were your questions answered in a way you could understand?</td>
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*Please provide any comments in response to your answer to question 3*
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<td>4.</td>
<td>Do you feel there was enough contact between you and the research staff?</td>
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<td>5.</td>
<td>Did you experience any problems getting to the research appointment (e.g. parking)?</td>
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<td>6.</td>
<td>Was the time and date of your appointment suitable and appropriate?</td>
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<td>8.</td>
<td>If you were interested, do you know how to find out the results of the study?</td>
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<td>Would you recommend taking part in this research study to other eligible people?</td>
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<td>10.</td>
<td>How did you find out about this study?</td>
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<td>11.</td>
<td>How else would you like to find out about other studies? (e.g. letter, email, phone, face-to-face, poster, website)</td>
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<td>12.</td>
<td>Would you please tell us why you agreed to take part in the study?</td>
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<td>13.</td>
<td>What would have improved your experience of taking part in this study?</td>
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</table>
14. Any other comments

If participating in research has had a positive impact on your life, we would like to learn more about your experience. To share your story, please provide your name and email address or phone number below and a NHS research team member will contact you:

To request a summary of the results from this survey, please email CRNEasternCommunications@nnuh.nhs.uk.

Thank you for taking the time to answer our questions
Your experience of taking part in research

Children and Young People

Thank you for taking part in this research study. Your help is really important and this questionnaire has been designed by the Clinical Research Network to find out what you think and feel about being involved in research. It is not part of the research you have taken/are taking part in.

You don’t have to fill it in but your answers will help us to improve clinical research and make future studies a better experience for people that take part.

When we are finished, we will write a report about what people said. Your answers will be kept private and future reports will not include your name.

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<thead>
<tr>
<th>Question</th>
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<th>Yes, mostly</th>
<th>Partly</th>
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<tbody>
<tr>
<td>1. Did you understand the study information you were given?</td>
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Please write anything else you want to say about question 3
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14. Is there anything else you would like to tell us about?

If taking part in research has had a really good effect on your life, we would love to learn more about your experience. To share your story or to request a copy of the results of this survey, please email us at CRNEasternCommunications@nnuh.nhs.uk.

Thank you for taking the time to answer our questions