



making patients' views count

Development and pilot testing of the questionnaire for use in the acute adult inpatients survey

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1 Executive summary

This report outlines the results of the research undertaken to develop and test the Inpatient questionnaire for use in the NHS patient survey programme. This development builds upon previous patient surveys carried out in acute trusts, especially the 2002 Adult Inpatient survey and the 2004 Adult Inpatient survey. This questionnaire is being designed for use in the Adult Inpatients survey 2005, and work on the development of the questionnaire and survey methodology began in January 2005, and a pilot survey was carried out in three acute hospital trusts in summer 2005.

Some minor alterations were made to the questionnaire and guidance based upon feedback from the Healthcare Commission and the Department of Health, before all documents were submitted to the North West MREC for ethical approval prior to the start of the national inpatients survey in September 2005.

This report describes the methods and results of this research work to date.

1.1 Aims

The aims of the survey development work were:

- Where possible, to keep the same questions as were included in the 2004 questionnaire. This will facilitate year-on-year comparisons.
- To capture a greater understanding of the elective and emergency inpatient pathway.
- To collect additional information about the sample, to allow a more detailed analysis at national and local levels
- To ensure that the questions are in line with current policy.
- To remove some questions from the core questionnaire which were not useful for performance indicators or quality improvement purposes. Any questions that are removed from the core questionnaire will be retained for optional use in the question bank.
- To use the inpatients pilot survey 2005 to identify issues with the current core questionnaire, and correct and improve where required.

1.2 Methods

- Consultation with the Healthcare Commission and experts in the field of acute inpatient experience to identify key issues and targets
- First stage of modifications of questionnaire and guidance
- Cognitive interviews with people with recent inpatient experiences to test the face validity of the questionnaire
- Postal survey in three acute hospital trusts (summer 2005)
- Further consultation with the Healthcare Commission and Department of Health to finalise questionnaire
- Submission to North West MREC committee for 23rd August 2005 meeting for questionnaire and cover letter amendments
- Final preparation of guidance documents for the start of the Inpatients survey 2005

1.3 Results

The cognitive interviews highlighted key issues that were important to those who had experienced an inpatient stay and clarified the phrasing of some questions. As this was the third year an inpatients survey had been developed, many of the questions had been assessed already. There were 28 new questions though, and one with new response options from the previous inpatients survey. Minor alterations to the questionnaire were made based on the findings of these interviews.

For the pilot survey, the questionnaire was sent to inpatients who had at least one overnight stay at three NHS hospital trusts (n=300 at each Trust). Response rates in the three trusts were 70%, 67% and 59%. There were few calls compared to other surveys of NHS patients to the FREEPHONE help line, which service users were invited to call if they had any problems, questions or complaints.

2 Changes to 2004 questionnaire (pre-pilot)

2.1 Questions on the ambulance services

The design of the new questionnaire allows the opportunity to ask patients questions on their experience of the ambulance service. Questions on the ambulance service were selected by using an ambulance survey importance study (carried out in 2003), where patients had rated which questions they thought were most important. These included:

- The ambulance crew making me feel reassured
- The ambulance crew giving me enough information about my condition and treatment
- The ambulance crew giving me pain killers
- The ambulance crew treated me with respect and dignity

Other questions that were high up in the importance study (eg the ambulance arriving quickly enough, trust and confidence in the ambulance crew's professional skills) demonstrated a distinct ceiling effect. For example, the 2004 Ambulance Survey report revealed that only 1% of patients reported that they did not have trust and confidence in the ambulance crew's professional skills. Therefore it is felt that asking these questions again is of limited use.

In addition we have included the question, "Did the ambulance crew talk in front of you as if you weren't there?" which did not feature in the importance study. The 2004 ambulance survey reported that 7% of patients felt the ambulance crew definitely talked in front of them as if they were not there, and a further 7% felt that this happened to some extent.

2.2 Questions on the Emergency department

There are a set of questions aimed at inpatients' experience of the emergency department. Initially, patients are asked "Did you use the emergency department?" so as to filter out inpatients who were admitted in an emergency but did not use the emergency department. The following three questions were used in the previous (2004) inpatient survey and consequently have been included again.

- How organised was the care you received in Accident & Emergency (or the Medical Admissions Unit)?
- Following arrival at the hospital, how long did you wait before getting to a bed on a ward?
- From the time you arrived at the hospital, did you feel that you had to wait a long time to get to a bed on a ward?

Three additional questions were added from the latest emergency department survey (2004/05). Only this selection were chosen to avoid confusion with asking similar question later on in the questionnaire (ie it would be confusing to ask (i) how clean was the emergency department? and (ii) how clean was the inpatient department?).

- Did you think the order in which patients were seen in the emergency department was fair?
- While you were in the emergency department, how much information about your condition or treatment was given to you?
- Were you given enough privacy when being examined or treated in the emergency department?

2.3 Before your admission

These questions are all about choice. 'Were you given a choice about which hospital you were admitted to?' and 'Were you given a choice of admission dates?' were already included in the 2004 inpatient survey. We were able to expand this section by including two additional questions: 'Overall, did you get enough information about the different hospitals to make your choice?' and 'Was the information about different hospitals easy to understand?'

2.4 Waiting

Compared with the 2004 Inpatient survey, there was only one change to the questions about waiting: 'Overall, from the time you were first told you needed to be admitted to hospital, how long did you wait?' This question was included to assess the government target that no inpatients should be waiting more than nine months for an inpatient admission.

2.5 Food

Alex Kafetz (HealthCare Commission) suggested a question on nutritional standards of food.

- Were you able to get healthy meals from the hospital menu?

Alex Kafetz (HealthCare Commission) suggested that patients need to be asked whether they received the help they needed in eating their meals

- Did you get enough help from staff to eat your meals?

This question tackles a combination of issues (ie patients whose food is left so long that it becomes cold, and patients not eating enough because nurses were not spending enough time helping them eat)

2.6 Hand washing

- As far as you know, did doctors clean their hands between touching patients?
- As far as you know, did nurses clean their hands between touching patients?

The emergency and outpatients surveys (2004/05) reported that patients thought that cleanliness of hospitals was deteriorating. This reflects patients concern with cleanliness in hospital, especially in light of the high profile MRSA media coverage. Patients need reassurance that hospitals are clean. Thus it is essential that we address this public concern by asking arguably the more important question on hand washing. Despite obvious limitations of this questions (ie sinks outside room, hospital staff bring discrete when cleaning hands), this question tackles patient concerns ie if the sink is outside room it will force doctors/nurses to adopt better practice by being more 'obvious' about cleaning hands, so that patients are reassured.

2.7 Operation and procedures

This section was added to assess whether staff are obtaining appropriate consent when required.

2.8 Leaving the hospital

Q62 asks patients whether or not they were given clear written information about their medicines. Previous national surveys have highlighted that patient discharge is an area of concern. The inclusion of this question will allow clearer identification of the sources of this problem.

2.9 Overall

- Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?

This was suggested by Alex Kafetz (HealthCare Commission). It is a national requirement.

- During your hospital stay, were you ever asked to give your views on the quality of your care?

If patients were asked to give their views on the quality of their care before they left hospital, problems could be tackled much more efficiently. Including this question will push hospitals to address this issue.

3 Questions that were removed

3.1 Emergency

- How organized was the care you received in the Accident and Emergency?
- During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?
- Were your scheduled tests, x-rays or scans performed on time?

Feedback from trusts revealed that these questions had limited value when it came to using the results from these questions to apply to quality improvement measures. These questions have not been used as performance indicators in previous studies. Consequently, due to competition for space in the questionnaire, it was decided that these questions could be removed.

4 Minor changes to existing questions

Q1. Was your hospital stay planned in advance or an emergency?

The response options to this question were changed so that they were more concise. Note that this is necessarily a problematic question, as it is necessary to channel patients through the emergency or planned admission sections of the questionnaire at the beginning, but patients come into hospitals in a variety of non-standard methods and it is difficult to capture this.

The question now reads as follows:

- 1 Emergency or urgent → Go to 2
- 2 Waiting list or planned in advance → Go to 12
- 3 Something else → Go to 2

5 Additional sample information

The HealthCare Commission has proposed that we collect extra sample information for the forthcoming Adult Inpatient Survey. The HealthCare Commission would like to collect information on specialty, PCT of residence and Length of Stay (LOS) of each patient to allow more detailed analysis. The aim of this section is to assess the practicalities of collecting this information.

5.1 Specialty

How is specialty recorded?

In April 2004 the National Specialties list was updated by the NHS Information Standards Board. The National Specialty List is a list of Specialty Function Codes for Medical & Dental specialties used for recording the main specialty of the consultant and the treatment specialty for the patient in Health Care systems and transmitted in Central Returns and Commissioning Data Sets.

The information is used mainly for activity analysis and workforce planning.

Standard - Specification

1. **Main specialty** – this is the specialty in which the consultant is contracted or recognised.

It relates to Workforce planning and will align to the same set of specialties as recognised by the European Specialist Medical Qualifications Order 1995 and European Primary and Specialist Dental Qualifications Regulations 1998. As its use is restricted to hospital consultants it will also include pseudo codes to identify Nurses, Midwives and other Health Care Professionals as required.

2. **Treatment specialty** – this describes the specialised service within which the patient is treated.

The list of valid specialties has been renamed “Treatment Function” and updated to include new treatment functions and exclude non-treatment functions. The activity of non-medical & dental staff can be described using treatment functions eg main specialty – Nurse; treatment function – Gastroenterology.

Each trust is required to send this information to the NHS Wide clearing service monthly (for each consultant episodes).

Having spoken to the Barbara Foggerty at the NHS Information Authority, she felt that all trusts should be able to provide ‘main specialty’ and ‘treatment function’ on admissions and discharge. She estimated that 90% of the time ‘main specialty’ is the same as ‘treatment specialty’, although there is probably more relevant information in treatment specialty. However some trusts still use old coding system. Therefore she said that ‘main specialty’ is safer to use, because there were fewer changes between old and new codes made to this.

Feedback from Trusts regarding specialty

We contacted a number of individuals (mainly from IT Department) from various trusts who are responsible for drawing the patient sample.

- three trusts thought it would be easier to produce specialty on admission rather than discharge

- two trusts reported that finding out the specialty on discharge would not be a problem
- one individual spoken to who draws the sample does not actually work in IT department. Consequently he would find it very difficult to draw this information.
- one trust spoken to still uses the old coding system and believed that a number of other trust would be in a similar situation.
- two individuals from different trusts who are responsible for drawing the sample had heard of 'main specialty' but had not heard of 'treatment specialty'.
- one trust was still trying to implement 'treatment function'. Consequently they thought that at present there was a data quality issue.
- two trusts were unsure if this was feasible because they are currently updating there PAS systems.
- one individual thought it would be more reliable to give specialty on discharge as opposed to admission, since patients were more likely to be coded correctly at the end of their stay.
- one trust thought it would be more reliable to have specialty on admission, since some patients may come in for say a heart operation but following this will be seen by a physiotherapist, so discharge information would not capture heart operation.
- two trusts thought that the specialty was not recorded efficiently, especially treatment function.
- Most of the trusts spoken to use local codes that are mapped to the national codes.

5.2 PCT of residence

Postcode information can be used to find out PCT of residence. The National Administrative Codes Service (NACS) provides postcode files which link postcodes to PCT OF RESIDENCES. Most trusts appear to have a system already set up to do this as this variable is a requirement of the Commissioning Data Set (CDS) and the NHS-Wide Clearing Service. The NHS Information Authority recommends continuing to use the 3 character code (using the first 3 characters) as opposed to the 5 character code.

5.3 Length of Stay

To calculate this, trusts should subtract the admission date (day/month/year) from the discharge date (day/month/year). For example, if discharge date =

15/7/2005 and admission date = 14/7/2005, the Length of Stay = 1. There could be some problems if all trust do not follow this calculation strictly (eg we would see different results if LOS was calculated in hours). To test this we will ask for the admission date, discharge date and length of stay in the pilot survey.

6 Testing the questionnaire: cognitive interviews

6.1 Introduction

Ten cognitive interviews were conducted over a period of a month in April-May 2005. The interviewees were recruited by placing adverts in local (Oxford) hospitals and newspapers. The sample was made up of 4 males and 6 females, with an age range from 27 years old to roughly 70 years old.

6.2 Results

Interview 1: white male, 27

The interviewee had recently been an inpatient for a twisted gut and liver infection for over a month.

General comments

The interviewee thought that the questionnaire was a “bit long”. He was unsure about which hospital experience to refer to as he was a frequent visitor. May be we need to re-emphasis ‘most recent stay’ in the first question.

Because the interviewee had been in two different hospitals at first he was unsure which one he should refer to – may be this need to re-emphasised ‘most recent’ in the first question:

- Was your **most recent** hospital stay planned in advance or emergency?

Interviewee spent a lot of time thinking about the question ‘As far as you know, did doctors wash or clean their hands between touching patients?’ Reason being interviewee thought that doctors did not often touch him; they would often just discuss condition. Therefore found it difficult to recall.

Interviewee found it much easier to recall nurses washing their hands simply because he saw them more often than doctors.

The interviewee found it difficult to answer the question 'Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way that you could understand?' The reason being he was too ill at the time to take anything in.

Interviewee did not like the word 'accurately' in the question 'Before the operation or procedure, did a member of staff tell you accurately how you would feel'. He did not think they could possibly know **accurately** how you would feel since all people are different and all operations are different.

When thinking about the question 'were you given clear written information about your medicines?' the interviewee was specifically thinking about the information written on the side of the bottle

Interview 2: black male, 30

The interviewee had recently been an inpatient for an infection on his leg.

General comments

Interviewee had to answer 'don't know/ can't remember' to the question 'As far as you know, did doctors wash or clean their hands between touching patients?' since there were no washing facilities in the room.

Similarly the interviewee answered 'don't know/ can't remember' to the question 'As far as you know, did nurses wash or clean their hands between touching patients?' since they tended to always use gloves.

Interviewee when answering the 2 questions on privacy which should be referring to the patients' inpatient stay he was thinking about the privacy he received in the Medical Assessment Unit – there was difficulty in distinguishing the 2 episodes.

Interviewee could not find a suitable response option to the question 'How many minutes after you used the call button did it usually take before you got the help you needed' as he was unable to use the call button due to disability.

Interviewee was unsure about '**operations and procedures**' – he had had an IV injection and was not sure if that classified as a 'procedure'

When thinking about the question 'were you given clear written information about your medicines?' the interviewee was specifically thinking about the information written on the side of the bottle.

'Did you receive copies of the letters sent between hospital doctors and your family doctor (GP)?' the interviewee felt that he could answer two options:

- No, I did not receive copies of any letters
- I do not know if any letters were sent

Interview 3: white female, 50

The interviewee had recently been an inpatient with a brain haemorrhage.

General comments

Interviewee missed the skip at the end of the emergency department questions – need to make this more obvious.

Had issues with the word 'bothered' in the question 'Were you ever bothered by noise at night from other patients/hospital staff?' Thought the verb was too negative.

Had problems with answering the question 'As far as you know, did doctors wash or clean their hands between touching patients?' because she was 'not always looking'. However she found it much easier to answer the same question referring to nurses

Interviewee was confused about the question 'How many minutes after you used the call button did it usually take before you got the help you needed?' She did not know if it was referring to the call button in the toilet or the one beside bed.

'Did you receive copies of the letters sent between hospital doctors and your family doctor (GP)?' the interviewee felt there should be an option:

- I did not want to see them

Or

- No, it was not necessary.

Interview 4: white female, 70

The interviewee had recently been an inpatient with two broken wrists.

General comments

Interviewee got confused by the question 'When you arrived at the hospital did you go to the emergency department (Casualty/A&E/Medical Admissions Unit)?' because she went to the 'Surgical Emergency Unit' – we updated the question to include this example

Interviewee missed the skip at the end of the emergency department questions – need to make this more obvious.

Problems with answering question 'As far as you know, did doctors wash or clean their hands between touching patients?' Interviewee could not remember because she rarely saw a doctor. However when answering the same question but referring to nurses she only felt comfortable answering this if she was 100% sure – and she felt she wasn't.

The interviewee was confused about the differences between the questions:

- 'Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?'
- 'Beforehand, did a member of staff explain what would be done during the operation or procedure?'

Interviewee did not like the word 'accurately' in the question 'Before the operation or procedure, did a member of staff tell you accurately how you would feel'. She did not think this was appropriate wording – too specific.

'Did you receive copies of the letters sent between hospital doctors and your family doctor (GP)?' the interviewee felt there should be an option:

- I received some but I do not know if that was all of them

Interview 5: white male, 40

General comments

Found it difficult to answer the question 'As far as you know, did doctors wash or clean their hands between touching patients?' due to problem of recall. However when answering the same question but referring to nurses he did not hesitate to answer this question.

Interviewee missed the skip at the end of the emergency department questions – need to make this more obvious.

Interview 6: white female, 35

The interviewee recently had a gall stone removed

General comments

She felt that the questionnaire at first was daunting (due to length) but after completing it found it content was good because most of the questions were applicable to her care. She got confused by all skips. She found it difficult to answer the question 'As far as you know, did doctors wash or clean their hands between touching patients?' She suggested that it would have been easier to answer this question if it read something like, 'Were you confident that doctors always washed their hands between touching patients?'

Interview 7: white female, 28

The interviewee recently had a stroke.

General comments

This interviewee had general problems recalling events. Found it difficult to distinguish emergency care from inpatient care. Interviewee had also recently been in hospital for something else and was unsure which care episode she should refer to.

Interview 8: white female, 50

The interviewee recently had an operation

General comments

She worked through the questionnaire without much problem. Except that she found it difficult to answer the question 'As far as you know, did doctors wash or clean their hands between touching patients?' (the interviewee took a long time thinking about it). Again took much less time answering the same question but referring to nurses.

Interview 9: white male, 40

The interviewee recently had a heart attack.

General comments

Unfortunately the interviewee was not very good at 'talking aloud' so got minimal information from him. However he did not appear to have any problems answering questions – did not spend too long on any particular questions, observed all the skips, approved of content and length of questionnaire.

6.3 Amendments to questionnaire following cognitive interviews

- 'Was your hospital stay planned in advance or an emergency?' was changed to 'Was your most recent hospital stay planned in advance or an emergency?' to re-emphasise the point.
- Include the 'surgical admission unit' in the question, 'When you arrived at the hospital, did you go to the emergency department (Casualty/A&E/Medical Admission unit/Surgical Admission unit)?'
- The skip after the emergency department questions was made more visible.
- 'Before the operation or procedure, did a member of staff tell you accurately how you would feel afterwards?' was changed to, 'Beforehand, were you told how you could expect to feel after the operation or procedure?'
- The responses to the question, 'Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?' were changed to:
 - Yes, I received copies
 - No, I did not receive copies
 - Not sure/ don't know

This is more concise and less confusion with different scenarios as discussed above.

6.4 Conclusions

The revised questionnaire includes almost all of the questions that were used in the 2004 core questionnaire and a number of additional questions. Any questions that have been removed from the core can be retained for optional use in the question bank, if trusts wish to make comparisons using those questions.

7 Mailed pilot surveys

7.1 Introduction

The acceptability of the questionnaire, and the sampling method were tested in mailed pilot surveys. Also, the response rates needed to be determined so that estimates for the national survey could be made.

7.2 Methods

Ethical approval was granted for the pilot study by the North West Multi-Centre Research Ethics Committee (MREC) on 10/05/05.

Three trusts (A, B and C) participated in the pilot. Once a copy of the letter showing ethical approval and the guidance manual had been sent to the trusts, their sampling was undertaken. All three trusts followed the guidance without reporting difficulty. One of the trusts was a specialist trust which handled some palliative care patients. Patients in the sample were assessed by their consultants, and any patients who were diagnosed terminal with very short life expectancy were removed from the sample. These patients were recorded with an “ineligible” outcome in the sample.

Each trust generated a list of 900 inpatients, consecutively discharged alive leading up until the last day of one of three months. This list was sent for tracing to NSTS

The three trusts were also asked for new information this year; the patient’s PCT of residence, the speciality on admission and discharge, and length of stay calculated from admission and discharge dates, which were also provided. One of the trusts had 100% concurrence between admission and discharge speciality. This was investigated and found to be an error at the trust where inpatient information was stored in ‘episodes’ of speciality. We asked this to be corrected, and they were able to send us a full data set with matched admission and discharge speciality for all patients. The guidance was modified to specifically prevent this happening in the national survey. Another trust asked specifically for one patient from their sample to be deleted from our records, due to very sensitive information that they could not reveal to us. This patient was deleted but not replaced; therefore that sample has 299 patients.

All three participating trusts agreed to allow Picker staff to organise the mailing of questionnaires. These staff members were given honorary contracts with the trusts to comply with the Data Protection Act. The first questionnaires were posted on 10/06/05, followed by first and second reminders (which are sent only to non-responders) to patients at all three trusts. The final cut-off date for inclusion was 15/07/05.

7.3 Results

Response rates

The response rates are shown in Table 1.

Table 1 - Response rates (15/07/05)

| | NHS Trust | | | Total |
|---|--------------------|--------------------|--------------------|---------|
| | Trust A (n=300) | Trust B (n=299) | Trust C (n=300) | (n=899) |
| Completed useable questionnaire | 203 | 195 | 174 | 572 |
| Returned undelivered | 2 | 4 | 6 | 12 |
| Deceased (reported by tracing services) | 12 | 2 | 1 | 15 |
| Opt out | 8 | 13 | 21 | 42 |
| Ineligible | 10 | 0 | 0 | 10 |
| Not returned yet | 65 | 85 | 98 | 248 |

| | | | | |
|-----------------------------------|-------------|-------------|-------------|-------------|
| Sum | 300 | 299 | 300 | 899 |
| Raw Response Rate (%) | 67.7 | 65.2 | 58.0 | 63.6 |
| Adjusted denominator | 288 | 280 | 293 | 861 |
| Adjusted Response Rate (%) | 70.4 | 69.6 | 59.4 | 66.4 |

These response rates suggest the overall response rates using this method will be approximately 60-70%. All trusts achieved a higher response rate than in the 2004 inpatients survey with the new twelve page questionnaire. In 2004, all three of these trusts used Picker as their approved contractor and used extra optional questions so that the 2004 questionnaire was also 12 pages.

Response bias

The proportions of respondents who were White British at Trust A, B and C were 8%, 96% and 86% respectively. Furthermore, 91% of all respondents to the pilot surveys who gave their ethnic group said that they were White British. This compares with 95% in the Acute Inpatient surveys 2004, 94% for the Acute Outpatient surveys 2004/5, and 93% for the Acute Emergency surveys 2004/5.

The samples contained approximately the same proportion of men and woman (48% and 52% respectively). Men comprised 47% of the responders, and woman 53%.

FREEPHONE calls

There were 12 recorded calls to the FREEPHONE concerning the inpatients pilot survey, which is 1.3% of the service users surveyed. The calls can be categorised as follows:

- There were 2 calls regarding questions about how to fill in the questionnaire
- 1 called to say that they had received the reminder but not first mailing. (These callers were informed that they will receive a second reminder, which will include a duplicate questionnaire in due course.)
- 1 said they were too ill to complete the questionnaire
- 5 opted out
- 3 were deceased, and we were advised by their relatives. None of these calls were upset or angry for receiving the questionnaire

In comparison, approximately 4% of patients participating in inpatient surveys call the FREEPHONE (ie 34 patients from a sample of 850). Therefore, the number of calls from the inpatients pilot is lower than that expected from a national survey of acute trust patients.

Respondents

Sample characteristics are shown in Table 2 - .

Table 2 - Basic characteristics of sample

| Sample Characteristics | Combined Trust samples (n=572) |
|-------------------------------|---------------------------------------|
| Gender | |
| Male | 47.7% (273) |
| Female | 52.3% (299) |
| Age (years) | |
| 16-35 | 11.4 % (65) |
| 36-50 | 19.2% (110) |
| 51-65 | 29.4% (168) |
| 66 years or older | 40.0% (229) |

Dimension scores and problem scores

The questionnaire was designed to investigate inpatients' experiences and to highlight any problem areas within acute NHS hospital services. The topics have been grouped into the five dimensions of care:

- Access and waiting
- Safe, high quality, coordinated care
- Better information, more choice
- Building relationships
- Clean and comfortable

The questionnaire was designed so that it could be analysed by dichotomous 'problem scores' indicating the presence or absence of a problem (see below). The problem scores on individual questions can then be summed together into five 'dimension scores' representing the above dimensions.

Examples of questions from the Inpatients Questionnaire showing deviation of problems scores

Black boxes indicate responses coded as a 'problem'.

Did doctors talk in front of you, as if you weren't there?

- 1 Yes, often
- 2 Yes, sometimes
- 3 No

During your hospital stay, were you ever asked to give your views on the quality of your care?

- 1 Yes
- 2 No
- 3 Not sure/Don't know

Did you find someone on the hospital staff to talk to about your worries and fears?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I had no worries or fears

Sixty-two of the questions in this questionnaire could be evaluated and were applicable to most respondents. Table 3 shows the percentage of inpatients in each trust who reported problems on this subset of questions.

Table 3 - Problem scores in three pilot trusts

| Question | A (n=203) | B (n=195) | C (n=174) | Total (n=572) |
|--|----------------------|----------------------|----------------------|--------------------------|
| Access and waiting | | | | |
| If you waited a long time before being admitted to a bed on a ward | 76.7% | 68.8% | 87.3% | 78.8% |
| If you felt you waited longer than necessary the waiting list | 7.9% | 30.6% | 50.0% | 21.7% |
| If your admission date was changed by the hospital | 11.4% | 25.0% | 44.4% | 20.6% |
| If you felt you had to wait a long time for a bed on a ward | 13.3% | 27.9% | 52.1% | 30.1% |
| Safe, high quality, co-ordinated care | | | | |
| Did not have trust and confidence in doctor's professional skills | 10.4% | 23.8% | 37.6% | 23.4% |
| Did not have trust and confidence in nurse's professional skills | 13.4% | 24.5% | 43.9% | 26.4% |
| If there were not enough nurses to care for you | 21.9% | 40.9% | 61.4% | 40.4% |
| If staff members said different things | 32.8% | 31.2% | 51.7% | 38.1% |
| If you had to wait long after ringing your call button | 69.9% | 89.9% | 84.2% | 79.8% |
| How long your discharge was delayed | 20.6% | 36.6% | 49.1% | 34.7% |
| If a member of staff did not tell you of danger signs to watch for at home | 34.3% | 56.8% | 73.2% | 53.6% |
| Better information, more choice | | | | |
| Not involved as much in decisions about your care and treatment | 24.9% | 50.5% | 78.8% | 47.0% |
| If the incorrect amount of information about your condition was supplied | 9.9% | 24.5% | 39.0% | 23.7% |
| The purposes of the medications have not been explained | 12.3% | 21.3% | 34.9% | 21.8% |
| Possible side effects of the medications were not told | 35.7% | 52.2% | 70.9% | 53.2% |
| Building relationships | | | | |
| Unable to get understandable answers to questions from doctors | 15.5% | 34.1% | 50.6% | 32.3% |
| Doctors talked about you as if you weren't there | 8.4% | 20.6% | 37.0% | 21.3% |
| Unable to get understandable answers to questions from doctors | 17.3% | 29.1% | 52.5% | 31.8% |
| Doctors talked about you as if you weren't there | 5.4% | 16.5% | 32.7% | 17.5% |
| If your family did not have the opportunity to talk to the doctor | 27.8% | 60.0% | 71.6% | 52.6% |
| Clean and comfortable | | | | |
| If the hospital room was not clean | 22.9% | 42.0% | 72.3% | 44.4% |
| If the hospital food was not very good | 60.8% | 71.5% | 93.1% | 71.5% |

| | | | | |
|--|-------|-------|-------|-------|
| If you were not given enough privacy when being examined or treated | 5.4% | 12.4% | 20.3% | 12.3% |
| If the hospital staff did not do everything they could control your pain | 12.8% | 30.1% | 44.8% | 29.6% |
| If you felt you weren't always treated with respect and dignity | 6.6% | 22.9% | 42.0% | 22.9% |

8 Problems noted following pilot

Q1 “Was your most recent hospital stay planned in advance or an emergency?” This skip proved difficult for many responders, possibly 10-20%. Often, someone would select option 2 (waiting list) and then go straight onto Q3 instead of Q12. When they get to Q11, few can miss the large Go to Q21, and we may be missing some waiting list patients – further analysis is needed.

Q12 “Were you given a choice about which hospital you were admitted to?” Two individuals stated the only *appropriate* hospital was the Royal Marsden. This may be the case for a few of the people going to specialist hospitals.

Q28 “Were you able to get healthy meals from the hospital menu?” It was common for people to write beside this question quantifying their answer. Often people would tick “No, I could not get healthy meals” AND “I did not eat hospital food”. It appears this is two distinct questions 1) whether the menu had healthy food, 2) whether or not they wanted/could eat it. This question does not answer what quality the food was either, ie taste, variety, temperature, etc. No questions on vegetarian options or diabetics either, both of which came upon few times in the comments.

Q32 “As far as you know, did doctors wash or clean their hands between touching patients?” (and Q37 for nurses). Comments were made by patients who thought they were unable to answer this question due to doctors and nurses wearing gloves instead of washing. It seemed patients believed this was as effective as washing hands.

Q58 “What was the main reason for the delay” (when being discharged from hospital). It was common for people to tick two of the options.

8.1 Changes

We have improved on the initial skips which caused problems by making the following changes:

- “Ambulance care” has been changed to “Emergency care” so that when directed by the skip on Q1 to go to Q2 for Emergency admissions, this title would concur with the response for that skip. Also, those ticking waiting list or planned admission would see a title which did not concur with their response.

- “Q7 When you arrived at the hospital, did you go to the emergency department?”, which previously had two responses with skips directing responders onto Q8 if they had, and Q21 if they hadn’t, has been amended to go to Q12 if they hadn’t come through emergency. This returns those who were incorrectly carried on past the first skip, to be directed back to the waiting list question options.
- The skip instructions have been changed following question 11 to: **EMERGENCY PATIENTS, now please go to Question 21, and WAITING LIST & PLANNED ADMISSION PATIENTS, please answer next section**

Q8 has been moved back three questions on the suggestion of the department of health because they felt it fit better in terms of patient journey at this point. We agreed and the question has now been moved to Q11, with Q9-11 becoming Q8-10.

Q12-15 (on patient choice) have been removed from the core questionnaire. This was requested by the Department of Health

Q16 has changed so that “Were you given a choice of admission **dates**?” becomes “...of **admission dates**?” This is now Q12 due to removed questions.

Two of the four responses of Q37 have been changed from font size 11 to font 12 for consistency. This is now Q32 due to removed questions.

Q28 (if healthy food was available) has been removed. This was requested by the Department of Health.

Two of the four responses of Q37 have been changed from font size 11 to font 12 for consistency. This is now Q32 due to removed questions.

Q58 was changed to emphasise that we sought a single main reason for the delay. The question was changed from “What was the main reason for the delay?” to “What was the **MAIN** reason for the delay?” This is now Q53.

Q75 and Q76 about disability have been added, as requested by the Department of Health.

Q75. Do you have a long-standing physical or mental health problem or disability?

- 1 Yes → Go to 0
- 2 No → Go to Error! Reference source not found.

Q76. Does this problem or disability affect your day-to-day activities?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

8.2 Question bank changes

Question B14 has been moved to a more appropriate position in the patient's journey, from B14 to B16.

Question B15 has been changed. The original question was "Were you able to get healthy meals from the hospital menu?" and has been changed to "Was there healthy food on the hospital menu?" This is because we felt the original question allowed too much interpretation of the question, and this was highlighted in the pilot. The third response option "No, I could not get healthy meals" has been changed to "No". The question now reads:

B14. Was there healthy food on the hospital menu?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know/ Can't remember

Question C5 originally read "Did doctors talk in front of you as if you were not there?" This has been changed to "Did doctors talk in front of you as if you weren't there?" to make it identical to the version of this question in the core questionnaire.

Question D4 originally read "Did nurses talk in front of you as if you were not there?" This has been changed to "Did nurses talk in front of you as if you

weren't there?" to make it identical to the version of this question in the core questionnaire.

Some text in question D5 has been made bold. It originally read "While you were in hospital, did nurses give you any information in a way which upset you?" and now reads "While you were in hospital, did nurses give you any information **in a way** which upset you?"

Some text in question E3 has been made bold. It originally read "How much information about your condition or treatment was given to you?" and now reads "How much information about your condition or treatment was given to **you?**"