Development and pilot testing of questionnaires for use in the acute NHS trust inpatient survey programme

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Executive summary

This report outlines the results of research carried out to develop, refine and pilot test the Picker adult inpatient questionnaire for use in the NHS patient survey programme.

Aims

The pilot studies had four main aims:

- To check whether any important items were missing from the original Picker questionnaire and to develop new questions covering topics not adequately covered in the original version
- To pilot four different length versions of the questionnaire, using random allocation within three hospitals to compare them against various criteria, including achieved response rates, proportion of missing response on each questionnaire, and concordance of responses
- To identify patients' top priorities among the topics covered in the survey
- To report the survey findings in three Trusts and to feed these back to the Trusts.

Methods

1. Mailed pilot test of 4-page and 12-page questionnaires, including one-page *What do you think of the inpatient questionnaire?* Survey
2. Focus groups with patients
3. Refinement of questions and questionnaires
4. Cognitive interviews with patients
5. Further refinement of questions and questionnaires
6. Mailed pilot of 8-page and 16-page questionnaires, including one-page *What do you think of the inpatient questionnaire?* Survey or one-page "*Which aspects of inpatient care are most important to you?*" survey

Results

The qualitative research did not identify any important items missing from the original Picker questionnaires and they performed well in the cognitive testing. All four versions of the questionnaire were acceptable to most respondents and item response rates were satisfactory. A few minor modifications were made following the first phase of the pilot testing and incorporated into the 8-page and 16-page versions of the questionnaire.

All four versions of the questionnaire (4-page, 8-page, 12-page and 16-page) produced acceptable response rates of more than 60% after one mailing and up to two reminders.

The pilot surveys in three NHS Trusts revealed high problem scores for some key areas. These scores were worse than the results obtained using the same Picker questionnaires in other countries. There is clearly a need to use the survey results to help staff see how things look through the eyes of their patients and to determine priorities for quality improvement. The next step, i.e. helping staff to use this feedback to initiate change, should be a key priority.

1 Introduction

This report outlines the results of research carried out to develop, refine and pilot test the Picker adult inpatient questionnaire for use in the NHS patient survey programme. The purpose of this pilot work was to ensure that the questionnaires met Department of Health (DH) requirements for the Acute Trust Surveys.

The study reported here had four main aims:

- To check whether any important items were missing from the original Picker questionnaire and to develop new questions covering topics not adequately covered in the original version

- To pilot four different length versions of the questionnaire, using random allocation within three hospitals to compare them against various criteria, including achieved response rates, proportion of missing response on each questionnaire, and concordance of responses

- To identify patients' top priorities among the topics covered in the survey

- To report the survey findings in three Trusts and to feed these back to the Trusts.

1.1 Original Picker questionnaire

The starting point was the UK Picker adult inpatient questionnaire, which was a British derivation of a questionnaire originally developed in the USA. The Picker Institute has developed a series of self-completion survey instruments to obtain detailed reports of patients' experience with specific dimensions of care. Instead of asking patients to provide satisfaction ratings, the surveys ask patients whether or not certain processes and events occurred during their care. Topics covered in the questionnaires were derived from extensive research to determine which issues patients deemed particularly important.[1] Survey instruments were then developed and extensively pilot-tested before making them available for routine use as a quality measurement tool. Picker surveys have been used since 1987 in hospitals in the USA and since 1998 in Germany, Sweden, Switzerland and the UK.

The conceptual basis and design of the questionnaires has been described elsewhere.[2] In brief, the development of the instruments involved defining the scope of the survey with the help of an expert advisory group, carrying out a literature review, conducting in-depth interviews and focus groups with patients to determine their priorities, producing an initial draft questionnaire, testing the draft using cognitive interviews with patients, redrafting and piloting the questionnaire before producing a final version. The adult inpatient survey has been refined using data from hundreds of hospitals that routinely use Picker surveys.[3-10] The standard Picker adult inpatient questionnaire is 12 pages long and includes 83 questions about patients' experience of their hospital stay plus demographic questions and a health status question. The survey covers seven dimensions of care:

- Information, communication and education
- Respect for patient's values, preferences and expressed needs
- Emotional support
- Physical comfort
- Coordination of care
- Involvement of family and friends
- Continuity and transition

1.2 Problem scores

The questionnaire is designed to be analysed by creating dichotomous 'problem scores' indicating the presence or absence of a problem (see below). The problem scores on individual questions can then can be summed into seven 'dimension scores' representing the dimensions listed above.

Examples of questions from Picker Adult Inpatient Questionnaire showing derivation of problem scores

Black boxes indicate responses coded as a 'problem'.

When you had important questions to ask a doctor, did you get answers you could understand?

1 ☐ Yes, always
2 ■ Yes, sometimes
3 ■ No
4 ☐ I had no need to ask

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

1 ■ Yes, often
2 ■ Yes, sometimes
3 ☐ No

Did you want to be more involved in decisions made about your care?

1 ■ Yes, often
2 ■ Yes, sometimes
3 ☐ No

1.3 Summary of pilot studies

a. Questionnaire development and validation

Qualitative research with patients was carried out to determine whether the topics included in the original Picker questionnaire were relevant and appropriate and whether any important issues were not covered. This included focus groups and cognitive interviews (See 2.1 - *Focus groups* and 2.2 - *Cognitive interviews* below). The focus groups addressed patients' experiences, concentrating especially on topics identified by DH as being priority issues. The groups also discussed priorities and carried out a simple rating exercise, where they were asked to rate the importance of specific topics. Cognitive interviews were conducted to test the comprehensibility of the new questions and the acceptability and structure of the questionnaires as a whole.

b. Deriving a 'core' questionnaire

In order to allow for some flexibility and to enhance local ownership, the intention of the DH was to offer Trusts a choice of three types of questionnaire:

1. A Core Questionnaire, which includes only the compulsory questions, some of which will contribute to the National Performance Assessment Framework.

2. An Enhanced Questionnaire, which include all the questions from the Core Questionnaire, plus further questions, selected by the Trust, from a validated Question Bank.

3. Subject to ethics approval, Trusts are also free to include their own additional questions if they wish and if they have the time and resources to carry out the necessary pre-testing.

The 40 problem scores derived from the original adult inpatient questionnaire were considered too numerous for use as performance indicators. It was necessary, therefore, to develop a rational basis for selecting a core set of compulsory questions for this purpose. We have used two different methods to derive a set of core questions:

a) Statistical techniques were used to derive a small number of indicators, which adequately capture the range of responses and can be used to predict the variation between Trusts and/or Health Authorities. Psychometric criteria were used to determine which topics should be included. This resulted in the removal of twenty-five items from the original forty topics, either because they were not applicable to a large proportion of respondents, or because their removal resulted in an increase in the reliability of the instrument. The remaining 15 items formed the core questions and were included in all versions of the questionnaires tested here.

b) We carried out further research with patients to determine their priorities, using simple ratings of issues relating to inpatient care. Focus group participants carried out a card sort exercise, which formed the basis of a further rating exercise in a survey of a much larger number of recently discharged hospital patients. The results were used to produce a list of topics ranked according to patients' estimates of their relative importance. The resulting hierarchy could be used to select the most popular elements for use as performance indicators. *(*See Section 6 - *Identifying patients' priorities.*)

c. Testing different versions of the questionnaire

The 4-page Core Questionnaire consisted of a total of 31 questions. These included all of the PPE-15 questions (see Section 5 - *Concordance of responses in different versions)*, and some additional questions, which covered DH policy priorities. Additionally, it included two "filter" questions, which were necessary to make the questionnaire flow properly, and to guide patients to answer only those questions that applied to them. Four demographic questions (on gender, age, education and ethnicity) and a single health status question were also included.

The 12-page Enhanced Questionnaire consisted of 108 questions. These comprised all of the 31 questions from the Core Questionnaire, and the remaining questions from the Picker standard questionnaire.

Firstly, mailed pilots of the 4-page Core Questionnaire and a 12-page Enhanced Questionnaire were carried out at two English inner city NHS Trusts (Trust A and Trust B). Patients recently discharged from these Trusts were randomly allocated to receive the 4-page or the 12-page version.

As a result of further qualitative research, the Core and Enhanced questionnaires were refined and two longer questionnaires were developed — an 8-page Extended Core Questionnaire and a 16-page Extended Enhanced Questionnaire. These longer questionnaires were then further tested in a mailed pilot in a rural English NHS Trust (Trust C).

With each of the four types of questionnaire, an accompanying one-page questionnaire was also included, entitled, *What do you think of the inpatient questionnaire?* This was concerned with opinions about the acceptability of the questionnaire, its length, and whether any important issues had been omitted.

1.4 Outline of procedure

In summary, the procedure was as follows:

1. Mailed pilot test of 4-page and 12-page questionnaires, including one-page *What do you think of the inpatient questionnaire?* surveys

2. Focus groups with patients

3. Refinement of questions and questionnaires

4. Cognitive interviews with patients

5. Further refinement of questions and questionnaires

6. Mailed pilot of 8-page and 16-page questionnaires, including one-page *What do you think of the inpatient questionnaire?* surveys or one-page "*Which aspects of inpatient care are most important to you?*" survey

1.5 Key issues

The purpose of this work was to investigate the following issues, some of which relate to the wording of the questions, and others, which are concerned with the overall structure and acceptability of the questionnaires as whole.

Questions

- Are the questions worded in a way that patients can understand?
- Are any questions redundant or offensive?
- Have any important items been omitted from the shorter versions?

Questionnaires

- What do patients think about the length of the different questionnaires?
- Do the "filters" work properly? That is, do patients correctly follow instructions to skip parts of the questionnaire that don't apply to them?
- Do the four versions achieve similar response rates?
- Do patients find all four versions equally acceptable?
- Are the questionnaires equivalent in terms of data completeness i.e. numbers of missing responses?
- Are there any other problems with the design of the questionnaires?
- Do the different versions achieve similar results from the questions that are common to all of them?
- Can patients rank the various topics included and, if so, what are their top priorities and what is less important to them?

2 Questionnaire development and validation

2.1 Focus groups

Introduction

Focus groups were used as part of the original testing and validation procedure in the development of the Picker questionnaire. In this study, additional focus groups were carried out to investigate the following issues:

- What issues are important to patients receiving NHS inpatient care?
- Which are the *most* important issues to patients?
- Are any of the issues covered by the existing Picker Inpatient questionnaire unimportant or irrelevant to patients?

The DH had also suggested that some issues were not adequately covered by the existing questionnaire, and that modifications to some of the questions might be necessary. Specifically, the following issues were highlighted for particular attention in focus groups:

- Waiting on trolleys in accident and emergency departments
- Cancellation of planned admissions
- Information patients would like to receive before a planned admission
- Information patients receive about hospital rules.

Method

Recruitment

Advertisements were placed in local Oxfordshire papers and a local radio broadcast was made. Posters and leaflets were distributed to GP surgeries and other health care facilities. Volunteers who had recently been discharged from hospital were asked to join a discussion group to talk about their inpatient experiences. They were asked to call a Freephone number and were told that people who attended the groups would receive a £25 gift voucher and reimbursement of travel expenses.

A number of criteria were used to check the eligibility of callers to take part in the groups:

- Were they adults (over 16)?
- Had they been an inpatient in the last year?
- Had they stayed overnight in hospital for at least one night?
- Was their stay in a general (i.e. not psychiatric, or maternity) ward?

Of the 37 people who responded to the advertisements, 11 were ineligible for one of the reasons outlined above, while 26 were eligible to attend. Of those, 21 thought they would be able to attend on one of the available dates. A total of 19 participants actually attended one of three focus groups, which were held in September 2001 in Oxford.

Participants

The three focus groups each comprised 5 to 7 participants. In total, 11 women and 8 men attended. Ages ranged between 33 and 85 (mean age 61). Pressure of time precluded organisation into specific groups by age, sex or social class. The focus groups were therefore heterogeneous.

Procedure

A female researcher with previous experience of running focus groups moderated the groups. The discussions were recorded on audiotape, and transcribed *verbatim*. The groups were structured around the focus group Topic Guide (see Appendix B). The procedure was as follows:

1. Participants were asked to discuss their hospital experiences, focusing on their experiences in Accident and Emergency (A&E); the information they received prior to admission, the planned admissions process, and the information they received about hospital rules.

2. They were asked to perform a card sort exercise to rank the thirty aspects of inpatient care in order of importance. The 30 items included in the card sort exercise are listed in Appendix B. Participants were asked to sort the cards into three groups:

    - Most Important
    - Quite Important
    - Least Important

The participants then discussed their ratings and reasons for them, focussing in particular on their "Most important" issues. They were also asked to say if they thought any important issues had not been included in the cards, or if any of the cards covered unimportant issues.

Analysis

Planned admissions

Much time was spent discussing how participants had been admitted to hospital. In the majority of cases, the admissions had been planned, but the groups also included some participants who had been admitted via A&E. Some patients had had their operations cancelled, and commented on this. Others thought their wait had been too long:

> *I have been to [Hospital X] and [Hospital Y]. [Hospital X] was the worst. Although I was totally blind in my right eye, I had to wait over a year for an appointment to go up there. You have to wait all day in there and then they said you've got a 7-month wait for the operation.*

However, the majority of participants who had planned admissions were happy with the procedures around their admissions:

> *It was at [Hospital X]. It was very quick. I went to see my doctor because I had this sort of seep in my eye when I woke up and she referred me to the hospital. I was there within about five days and an appointment was made for me to have an operation in three weeks, which is very good.*

> *Well I got the letter to ring the day before and report at this time. I did everything and it all went exactly as it said in the letter. I got to the nurses station and I was admitted instantly. In fact my bed was there waiting for me and that was it. And I had the operation exactly when they said which was the next morning. So it was exactly as I was told it was going to be and there was not a minute's time wasted.*

Emergency admissions

There were a wide variety of evaluations of the emergency admissions procedures. Some had not encountered any particular problems, or were not inclined to complain about their wait:

> *I was fetched in off the street so from their point of view it was a surprise. They took me into casualty, referred me to a semi casualty place and then they investigated and then up to the ward. I mean there was no plan at all. I was ill and they just took me in and straight up, no problems.*

> *There was a bit of a wait, but it was damn busy in there and there were people far more ill than me. Well in fact they were fighting for a baby's life at one stage, so I didn't mind waiting did I?*

For others, the experience was less positive:

> *I was actually in the Accident & Emergency for 30 hours, the main part, and they then told me they were then moving me temporarily before I went up to a ward into a side unit, which is the self harm, because there was a space in there and that I would be there for a few hours before they found me a bed. And I was there for five days. There was no call buttons. I was barely seen by the doctors because it was not on the normal rounds. I was verbally abused by the other patients because they had their own problems. I felt sorry for them being treated because it was quite horrendous. And that was where I was left for five days before we actually said that we were physically going to remove me from the hospital unless somebody actually did something and senior management finally found me a bed on the Saturday and I had been in there since Monday and I had had dreadful treatment and I was not very happy, as you could imagine.*

Trolleys

Few participants were able to describe experiences of trolley waits. However, those who had waited on a trolley had quite different evaluations of their experiences. Some patients found it quite acceptable. For example:

> *I was on a trolley all the time.*

Q: And how was that?

No problem I wasn't bothered about it because they were coming in and seeing and checking all the time.

One man gave a very positive account of his trolley wait:

Well I was waiting on a trolley and I had heard people say "I went into hospital they put me on a trolley and left me in a dingy noisy corridor for ages", which is a dismal account. It was not gloomy and, to explain: Trolley: a snugly designed wheelie bed with reassuring side gates. Dingy: plain and easy to keep clean. Noisy: the bustle of vital work. When you aren't well, sounds fade into the background. Corridor: a space where passing observers are never far away. Ages: time for you to catch up on some rest while waiting for help.

I do feel wounded when people say, "They pushed me on a trolley and left me in a corridor." I mean, it makes people think that they rejected you, but those trolleys cost £350 a piece. When you say trolley it sounds like something a kid has knocked together that they play on the street with. Those beds are cleverly made and they are so comfortable and you just let go and the fact that it is a narrow bed of course, but you have got these side gates. You think nothing matters and you can just let go. That is what you want when you are not well.

One patient did not complain about the wait, despite it lasting for 8 hours, but felt that her daughter's assistance had been an important part of her care, and that other patients had not had the same advantage:

Yes, I waited about 8 hours on a trolley. I had gone into hospital as an emergency because I couldn't stand up. I was put on a trolley in a cubicle and my daughter was with me all the time and that was fine but I know that some people didn't have anyone with them on a trolley and they wanted a drink of water, say, and everybody was so very busy and didn't want to bother. My daughter was going round all the time to people who were on their own.

Another patient noted that the definitions of "trolley" and "bed" were sometimes unclear:

I was actually still on the Accident & Emergency trolley but it was an advanced trolley and as far as they were concerned it was a bed, but it wasn't a bed, it was actually a trolley.

Information

Participants were asked how much information they were given before planned admissions to hospital. Some participants had visited the hospital prior to admission. Overall, the responses were positive with many participants confirming that they had received a booklet about the hospital and information regarding their medical procedures in advance of being admitted:

I was given absolutely everything that I wanted to know.

I have had private and I have been in the NHS. I went into [Hospital W] through the NHS when I snapped both the ligaments in my knee and it was all explained to me before I got in for the operation what they were going to do. And when I went in that morning before the op and had the pre-op, they explained everything. The paperwork was good: how to get there; what to do when you get there. It was no different to being in private.

A whole booklet, what to bring when you are admitted, the doctors, the anaesthetists, the whole lot.

And particularly when you have a hip or possibly a knee done they send you a booklet what to expect when you come into hospital.

Including the buses even the buses.

Yes I was taken to the ward before I went in and introduced to everybody and shown around, had a cup of tea and a chat it was absolutely fantastic. And then the Friday before the operation on the Monday, I went up and had all the tests as well. So when I got in there I was quite familiar with everything.

Rules

Participants were asked if they were informed about the rules of the hospital. Most confirmed that the rules such as meal times and visiting hours had been set out in the information booklet if they had received one. No one commented about knowing or understanding the rules of the hospital.

Card Sort Analysis

Participants were asked to comment on the issues they had rated as 'Most Important', and to state whether any important issues had been left out. None of the participants commented that they thought anything important had been left out. A few commented that one or two issues were not important to them, but there was no consensus on which issues were unimportant.

Top priority items

At the end of the card sort exercise, participants were asked to select one single item from their most important pile that they considered to be their top priority, and to comment on why it had been important. The following items were selected:

Cleanliness

Several patients commented on the dirtiness of the hospital, and many were concerned about the implications for infection control.

Cleanliness of hospital. I think is paramount and I think one of these super bugs is one of the problems. One of the problems that does concern me is that nurses, they don't sit on the bed, the doctors sit on the bed, they then go from patient to patient and I strongly suspect that bugs are transported from one to another.

I don't know if you saw the graph in one of the papers [Hospital Z] was one of the dirtiest.

Dignity and respect

Being treated with dignity and respect I think is very important whoever you are.

Discharge

A number of patients felt that the discharge arrangements were disorganised and that they had been treated discourteously.

I think there is not enough care given to you when you are about to come home. You are not given the right instructions. It seems as if once a decision is made that somebody is going to fetch you they can't wait to get you out of the wards as quickly as possible because obviously the bed and the nurses' time is occupied elsewhere.

Recovery at home

Some patients commented that post-discharge information was the most important thing for them.

It's your plan for the rest of your life to really get back on top and stay there.

Because basically when you are in hospital it is all taken care of really. I mean, when you get home you are on your own. There is no doctor there that you can press a button and the doctor comes or anything else.

Waiting for admission

Many participants commented on pre-admission waiting times.

I think given the date for the operation and the hospital keeping to that date.

To be able to get in quicker.

I think probably the admissions. I think that has got to be brought down a bit if they are going to make appointment then okay, I know, to a certain extent they have got to be cancelled and all the rest of it but they seem to be going over the score. It is not just once it is getting cancelled, it is two and three times.

That you get in within reasonable time, if they give you a date and then you are cancelled the first time then I don't think you should be cancelled a second time because the anxiety that it causes not just in the person it is for, it is the family concerned and everything.

Food

Food was highlighted by some patients. Their concern was not only to receive appetising food, but to get food appropriate for their dietary requirements, and to receive adequate nutrition to promote their recovery from illness.

Good food. If you don't have good food you don't survive do you!

Further research on priorities

The results of this exercise suggested that patients were able to understand and engage in the task of rating patient issues. Also, the 30 cards adequately covered the range of issues that patients thought were important. Therefore, a larger group of recently discharged inpatients were asked to rank the same 30 issues in a postal survey. This exercise is described in Section 6 - *Identifying patients' priorities.*

2.2 Cognitive interviews

Introduction

Cognitive interviews were carried out to test patients' understanding of the Core and Enhanced questionnaires. On the basis of the results of the focus groups and the analysis of the *What do you think of the inpatient questionnaire?* data, some of the existing questions were re-worded and some new questions were added. Additionally, the 1991 Census question on ethnicity (which has 6 response options) was replaced with the longer 2001 Census question (which has 16 response options), and the single health status question was supplemented with five health status questions - the *EQ5D*. The extended questionnaires were 8 and 16 pages long. Following the cognitive interviews, further minor modifications were made. The modifications made before and after the cognitive interviews are summarised in 2.3 - *Modifications to questionnaires.*

Method

Participants

The recruitment method and the criteria for inclusion in the interviews was the same as for the focus groups. Eight people, 3 men and 5 women, who had recently been inpatients in NHS hospitals agreed to be interviewed. Ages ranged between 33 and 86.

Procedure

Two researchers - one male and one female - carried out the interviews. Five participants completed the 16-page questionnaire, while 3 completed the 8-page version. Participants were asked to complete one of the questionnaires, then the interviewers read through the responses with the participants, and discussed their responses. The following issues were addressed:

- Did the responses on the questionnaire match with the verbal accounts given by patients?
- Were the instructions clear and did participants follow them appropriately?
- Were any of the questions difficult to understand?
- Were the response options adequate?
- If a question had been omitted (rather than skipped because it did not apply), what was the reason?
- Did the questions adequately reflect what was important to them about their inpatient experiences?

Analysis

Overall, the participants found the questionnaire to be clear, understandable and appropriate. None of the patients commented that they found any of the questions to be offensive. A few problems were encountered in completing the questionnaire, and some inconsistencies were noted between verbal accounts and written responses.

In the following report, questions will be identified by their number in the sixteen-page questionnaire, in the style A1. The question numbers for the eight-page version are numbers only, rather than letters and numbers.

Comprehensibility

Emergency or planned admission

A few problems were identified with the following question, which was included in both the 4-page and 12-page versions of the questionnaire:

A1. Was your hospital stay planned in advance or an emergency?

1 ☐ Planned in advance

2 ☐ Emergency

3 ☐ Something else

This was amended for the 8-page and 16-page questionnaire as follows:

A1. Were you admitted to the hospital as an emergency or after dialling 999, or was your admission from a waiting list or planned in advance?

1 ☐ Emergency/dialled 999/immediately referred

2 ☐ Waiting list or planned in advance

However, this amended question still presented some problems. It was left blank by one patient, who answered questions in both the *Emergency or immediately referred* and *Waiting List or planned admission* sections (which are intended to be mutually exclusive). Another patient answered *2- waiting list* to the above question, but also responded to questions in the emergency section of the questionnaire. [1]

Information questions

The following questions, which are included only in the 16-page version of the questionnaire, were answered wrongly by one interviewee:

A10.	Before being admitted to hospital, were you given any printed information about the hospital?
A11.	Before being admitted to hospital, were you given any printed information about your condition or treatment?

His answers were transposed, such that he answered *Yes* to A10, where the true answer was *No,* and *No* to A11, where the true answer was *Yes.*

Response options

Noise questions

Two of the interviewees commented that the following question posed a problem:

B8. Were you ever bothered by noise **at night**?

1 ☐ No

2 ☐ Yes, from other patients

3 ☐ Yes, from hospital staff

4 ☐ Yes, from something else

[1] The acceptability of the different versions of this question will be examined further through the analysis of the quantitative data in Section 3.

They commented that the noise had come from more than one source. Accordingly, one interviewee ticked two boxes (2 and 3), even though the instructions did not suggest that respondents could tick more than one box.

Scope of questionnaire

Different members of staff

One patient commented that the questionnaire did not allow them an opportunity to distinguish between different members of staff. They noted that they had received very different treatment from the different doctors and nurses who cared for them.

Two interviewees commented on standards of care and courtesy they received from other members of staff, such as porters, catering staff and cleaning staff. They thought the questionnaire should cover these staff, as well as nursing and medical staff. This issue had also been raised in the focus groups.

Food

In common with the focus group participants, a number of interviewees commented that food was a particular problem in hospitals. Some interviewees thought there should be more questions to reflect the importance of this issue.

Admissions

Some of the respondents commented that they had had to make considerable efforts to get admitted to hospital. For example, one interviewee felt that she would not have been admitted without her own efforts in calling a consultant's secretary and persisting in her request to be put on a waiting list. She noted that the questionnaire did not ask patients to report on how easy it had been to get on to a waiting list in the first place.

2.3 Modifications to questionnaires

As a result of the findings of the cognitive interviews, focus groups and the responses to the *What do you think of the inpatient questionnaire?,* a number of modifications were made to the wording of the questions and the content of the Core and Enhanced questionnaires. Some of these modifications were in areas that had already been highlighted as topics for particular consideration, while other modifications emerged from focus group discussions and cognitive interviews. The additional questions and longer ethnicity and health status questions considerably increased the length of the questionnaires. The Extended Core Questionnaire was now 8 pages long, while the Extended Enhanced Questionnaire had 16 pages.

Instructions on questionnaire

The instructions on the front page of the questionnaire begin with the following statement:

> **What is the survey about?**
>
> This survey is about your most recent experience as an INPATIENT at the National Health Service hospital named in the letter enclosed with this questionnaire.

However, it was noted in the cognitive interviews that patients sometimes referred to other previous hospital experiences. For some patients, there was perhaps an eagerness to be helpful by answering as many questions as possible, even if a question did not apply for their most recent admission. In order to emphasise the importance of referring only to their most recent hospital admission, the following box was added at the beginning of the second page, before question A1:

> Please remember, this questionnaire is about your **most recent** stay at the hospital named in the accompanying letter.

Trolley questions

Three questions concerning waiting in A&E were added to the section covering emergency admissions in both versions of the questionnaires. These questions addressed the following issues:

1. How long was the wait?
2. Where did patients wait? (i.e. a cubicle, an open plan area or a corridor)
3. What did they wait **on**? (i.e. a bed, trolley or chair).

Cancellation of planned admissions

A question concerning cancellation of planned admissions was added to both versions of the questionnaire:

A9. Was your admission date changed by the hospital?

1 ☐ No

2 ☐ Yes, once

3 ☐ Yes, 2 or 3 times

4 ☐ Yes, 4 times or more

Information questions

The existing question concerning *the information sent to patients prior to planned admission* was divided into two questions. From the focus groups, it had emerged that hospitals sent out two different types of information to patients: information about *the hospital* and information about their *condition or treatment*.

Following the cognitive interviews, the formatting of the information questions was modified, so the different information types were emboldened, in order to reduce the possibility of confusing them. The new questions read as follows:

A10. Before being admitted to hospital, were you given any printed information about the **hospital**?

A11. Before being admitted to hospital, were you given any printed information about **your condition or treatment**?

Rules

The issue of hospital rules did not emerge as a particularly important issue in focus groups, and the interviewees did not comment on any difficulty in understanding the question. Therefore, this question was left unchanged. However, the lack of interest in this issue from the focus group participants suggests that this question could be omitted from both the Core and Enhanced versions of the questionnaire.

Additional questions

The focus group discussions and cognitive interviews identified a few issues that patients thought were important but that had not been included in the questionnaire. Further questions were therefore added to cover these issues. Similarly, the cognitive interviews highlighted some areas where re-wording and re-formatting could improve the readability of the questionnaire.

Different members of staff

Three new questions were added, to cover the courtesy of the three other types of staff mentioned most often by focus group participants and cognitive interviewees. The following questions were added to the 16-page version of the questionnaire:

B16. How would you rate the courtesy of the **catering staff**?

B17. How would you rate the courtesy of the **hospital porters**?

B18. How would you rate the courtesy of the **cleaning staff**?

Food

The following questions about food were added:

B12. Were you offered a choice of food?

B13. Did you get the food you ordered?

Noise

The two noise questions (one asking whether patients were bothered by noise from *other patients*, *hospital staff*, or *something else* **during the day**, the other concerning noise **at night**) were modified to allow for the possibility that patients were bothered by noise from more than one source. An instruction to *tick all that apply* was added to this question.

Ethnicity question

As noted above, the 4- and 12-page questionnaire included the 1991 Census question on ethnicity, which has 6 response options. For the 8-page and 16-page questionnaire, this was replaced by the longer 2001 Census question, which has 16 response options.

Health status question

A standardised five-item health status measure, the EQ5D, was added and inserted alongside the existing single item health status question.

Order of response options for questions in Section J

It was noted that, in the 12-page version of the questionnaire, the order of response options for two adjacent questions in Section J: OVERALL, was opposite for the two questions and this was a potential source of confusion. Therefore, the order of response options to the following question was changed:

> **J2.** How would you rate how well the doctors and nurses worked together?

In the modified 8- and 16-page versions, response order was changed so that *Excellent* was first, and the last option was *Poor*. This is consistent with the ordering of the responses for the following question:

> **J3.** Overall, how would you rate the care you received?

Acceptability of questionnaires

Length

All of the interviewees (using both the Core (8-page) and the Enhanced (16-page) questionnaires) said that the length of questionnaire was acceptable.

Acceptability of questions

None of the interviewees commented that any of the questions were offensive or redundant. Most interviewees did omit a few responses, even where those questions were apparently relevant to them. However, there was no consistency among interviewees in which responses were omitted, so it was not appropriate to make modifications on the basis of these omissions.

3 Postal surveys

As outlined above, the four versions of the questionnaires were sent to a group of patients recently discharged from inpatient care in NHS hospitals. The 4-page *Core Questionnaire* and a 12-page *Enhanced Questionnaire* were randomly allocated to patients from two English inner city NHS Trusts (Trust A and Trust B). The 8-page *Extended Core Questionnaire* and the *16-page Extended Enhanced Questionnaire* were randomly allocated to patients from a rural English NHS Trust (Trust C).

The procedure used to carry out these surveys was the same as the *Guidance on …. (website). That is, in each Trust a date was selected and patient information staff were asked to select the 750 [2] adult inpatients consecutively discharged prior to that date. Ineligible patients (for example, those who had died, maternity patients and private patients) were then excluded from the sample and questionnaires were mailed to the remaining patients, and non-responders were followed up with up to two reminders. The covering letters essentially were the same as those shown in the guidance material. The number of a fully staffed freephone helpline was also given in the covering letter, so that patients could call with any questions they might have.

3.1 Response rates

Table 1 shows response rates for each of the four types of questionnaire. It can be seen that response rates varied between 63% and 69% and they are highest for the 8-page questionnaire, followed by the 4-page, then the 16-page, and that the lowest response rate is for the 12-page questionnaire. However, direct comparisons are not advisable since the 4- and 12-page questionnaires were sent only to patients from inner city hospital locations, while the 8-page and 16-page questionnaires were sent only to patients from a district general hospital trust in a relatively rural location. Some of the variation in response rates must be accounted for by this difference of location.

A comparison of different lengths of questionnaire sent to patients within the same location shows that response rate on longer questionnaires tends to lower, but the size of this effect varies considerably between locations. For example, at Trust A the 12-page questionnaire received only 1% fewer responses than the 4-page version. On the other hand, in Trust B, compared to the 4-page version, 6.5% fewer patients returned the 12-page questionnaire.

Table 1 - Response rates for 4 types of Inpatient pilot questionnaires

	Pages in questionnaire			
	4	**8**	**12**	**16**
Trust A	64.2%	-	63.0%	-
Trust B	69.8%	-	63.3%	-
Trust C	-	69.0%	-	64.3%
Mean response rate	**67.0%**	**69.0%**	**63.1%**	**64.3%**

[2] The number of patients required for the NHS Trust Acute Inpatient surveys is 850.

3.2 Results - patient experiences at three Trusts

A subset of the questions was covered in all questionnaires and was applicable to all patients (that is, there were not designed to be skipped by any patients). For most of these questions, it was possible to compute a problem score (See 1.2 - *Problem scores* above). Table 2 shows the percentage of patients in each Trust who reported problems on this subset of 20 questions. One-way analyses of variance were carried out for each question, comparing problem scores among the three Trusts. The questions on which problem scores were significantly different are marked with an asterisk.

Table 2 – Problem scores in three pilot Trusts

Question	Trust		
	A	B	C
Bothered by noise at night *	44.0%	46.8%	51.5%
Ward not clean	62.0%	56.9%	58.4%
Toilets and bathrooms not clean	65.5%	59.7%	61.1%
Food rated fair or poor *	57.4%	59.2%	52.8%
Doctors didn't answer questions	38.8%	39.7%	37.8%
Doctors didn't discuss fears	43.7%	46.5%	42.3%
Doctors talked as if I wasn't there **	33.5%	40.6%	32.4%
Nurses didn't answer questions *	37.1%	33.6%	30.3%
Nurses didn't discuss fears **	47.9%	47.0%	40.2%
Staff said different things *	33.7%	39.3%	28.1%
Wanted to be more involved **	56.5%	58.5%	44.8%
Family didn't have opportunity to talk to doctor	44.6%	45.2%	46.8%
Couldn't find someone to talk to about concerns	45.0%	43.7%	42.6%
Asked name and address too often *	16.3%	12.3%	10.9%
Purpose of medicines not explained	20.4%	22.0%	18.8%
Not told about danger signals to watch for *	64.5%	64.4%	58.3%
Family not given information to help me recover *	47.7%	51.0%	43.4%
Staff didn't discuss social care needs with me *	20.3%	24.2%	18.4%
Overall, not treated with respect and dignity	29.2%	27.1%	25.5%
Overall care rated fair or poor	12.6%	11.3%	11.9%

* p <.05, **p <0.005

3.3 Missing responses to Inpatient questionnaires

Data from the four surveys were compared in order to test whether the length and structure of the questionnaires had any effect on the completeness of the data. That is, did patients tend to miss out questions more in some questionnaires than others? Again, for the purposes of this analysis, only those questions covered by all four types of questionnaire, and which it was not possible to skip, were included. Apart from the 20 questions covered by the problem score analysis above, it included two filter questions and three demographic questions. The ethnicity question was examined by aggregating data from the two different types of ethnicity question to see whether the design of this question had any effect on missing responses.

In particular, we were also interested in comparing the two different types of *Emergency/Planned admission* questions used in the 4/12-page and 8/16-page questionnaires. It was reported above that, despite some changes to this question, it still presented some problems in cognitive interviews.

Table 3 shows the percentages of respondents who missed responses to each of the 25 questions on each of the four types of questionnaire. All percentages above 5% are shown in **bold** type. It can be seen that overall percentage of missing responses in each questionnaire ranged between 1.9% on the 4-page questionnaire and 5.2% on the 16-page questionnaire. For all questions, there were more missing responses in the 16-page questionnaire than for any of the others.

Table 3 – Percentages of missing responses in four types of questionnaire

Question	Number of pages in questionnaire				
	4	8	12	16	Means
Was admission planned or emergency?	2.3%	**6.9%**	**5.6%**	**9.7%**	**6.1%**
Ever bothered by noise at night?	1.4%	1.8%	3.3%	4.4%	2.7%
How clean was the ward?	2.0%	1.4%	3.3%	3.8%	2.6%
How clean were the toilets/bathrooms?	1.2%	1.4%	1.7%	4.0%	2.1%
How would you rate the food?	1.4%	.8%	2.0%	2.9%	1.8%
Did doctors answer questions?	1.6%	1.6%	1.5%	**5.5%**	2.5%
Did doctors discuss fears?	1.4%	2.0%	2.4%	**5.5%**	2.8%
Did doctors talk as if you weren't there?	1.8%	2.6%	2.8%	4.8%	3.0%
Did nurses answer questions?	1.2%	.4%	2.0%	3.4%	1.7%
Did nurses discuss fears?	1.6%	2.2%	3.5%	4.4%	2.9%
Did staff say different things?	3.1%	1.0%	3.5%	**5.5%**	3.2%
Did you want to be more involved?	1.6%	1.4%	3.9%	**6.1%**	3.2%
Did your family have opportunity to talk to doctor?	2.0%	2.8%	3.3%	4.8%	3.2%
Did you find someone to talk to about concerns?	1.4%	2.2%	4.8%	**6.3%**	3.6%
Were you asked you name and address too often?	3.5%	2.2%	1.7%	**6.1%**	3.4%
Were you ever in any pain?	1.8%	4.7%	3.5%	**6.3%**	4.1%
Were medicines explained?	2.3%	1.4%	**5.2%**	**5.7%**	3.6%
Were you told about danger signals?	3.9%	4.7%	**6.5%**	**6.7%**	**5.4%**
Were your family given information to help you recover?	2.7%	3.5%	**5.6%**	**6.7%**	4.6%
Did staff discuss social care needs with you?	2.7%	3.0%	3.3%	**7.2%**	4.0%
Overall, were you treated with respect and dignity?	1.4%	3.0%	2.2%	**5.5%**	3.0%
Overall, how would you rate the care you received?	1.8%	2.2%	1.5%	3.6%	2.3%
Are you male or female?	1.0%	1.4%	3.9%	**7.6%**	3.4%
When did you leave full-time education?	4.9%	2.8%	**7.2%**	**9.3%**	**6.0%**
Ethnicity	3.5%	4.7%	3.5%	**9.7%**	**5.3%**
Means	1.9%	2.2%	3.2%	**5.2%**	**3.1%**

The questions for which the highest percentages of missing responses were recorded are discussed below.

Emergency or planned admission?

It is likely that the omissions in this section arise from the difficulty some patients have in categorising their admission. A significant minority of patients are admitted following an outpatients' appointment, during day care, or from another hospital and the existence of these non-standard admissions makes it very difficult to design questions that are appropriate to all types of admission. However most patients are admitted either through A&E or as planned admissions and questions specific to each of those types of experience need to be included in the questionnaires.

The number of missing responses for the version of the question used in the 8-page and 16-page questionnaires was higher than in the 4-page and 12-page version. It may, therefore, be advisable to return to the original question in future.

Were you told about the danger signals to watch for?

It is possible that some patients did not believe that there were, in fact, any danger signals to watch for, particularly if their admission had not been for surgery. They might therefore have found that none of the three response options (Yes, completely / Yes, to some extent / No) was appropriate to them.

When did you leave full-time education?

As was noted in the analysis of the *What do you think of the inpatient questionnaire?*, several patients commented that they did not consider this type of information to be relevant to their hospital stay and that they thought the question should not have been asked.

Ethnic question

Overall, the ethnicity questions received the highest numbers of missing responses, and this was particularly the case for the 16-option 2001 Census question than for the shorter 1991 census question. In common with the education question, this finding concurs with the results of the *What do you think of the inpatient questionnaire?*, where several respondents commented that the ethnicity question should not have been asked.

Differences between questionnaires

These results suggest that the overall proportion of missing responses increases with the number of pages in the questionnaire. This was particularly evident with the 16-page questionnaire, where the percentage of missing responses was, on average, 5.3%, compared to only 1.9% on the 4-page questionnaire.

4 What do you think of the inpatient questionnaire?

4.1 Introduction

An additional questionnaire was included with each of the four types of pilot Inpatient Questionnaires. This covered how long it took to complete the Inpatient Questionnaire, and evaluations of the length of the questionnaire. Respondents were also asked whether they thought any questions were difficult to understand, or should not have been included, and whether they thought any questions should have been included (but were not).

4.2 Respondents

The 4-page and 12-page questionnaires were sent to patients discharged from Trust A and Trust B. The 8-page and 16-page questionnaires were sent to patients from Trust C. Within each Trust, the different versions were randomly assigned to patients. A total of 2250 *What do you think of the inpatient questionnaire?* forms were sent to patients — 750 with each of the 4-page and 12-page questionnaires and 375 with each of the 8-page and 16-page questionnaires. Of these, 77 patients were excluded because they had died, questionnaires were returned undelivered or they were ineligible to take part in the survey. A total of 1347 useable forms were returned, representing an overall response rate of 62.0%. Table 4 shows the number of responses received relating to each different type of questionnaire.

Table 4 - Number of responses from the four questionnaires

Length of questionnaire	Number of responses to *What do you think…* questionnaire
4-page	474
8-page	235
12-page	434
16-page	204

4.3 Results

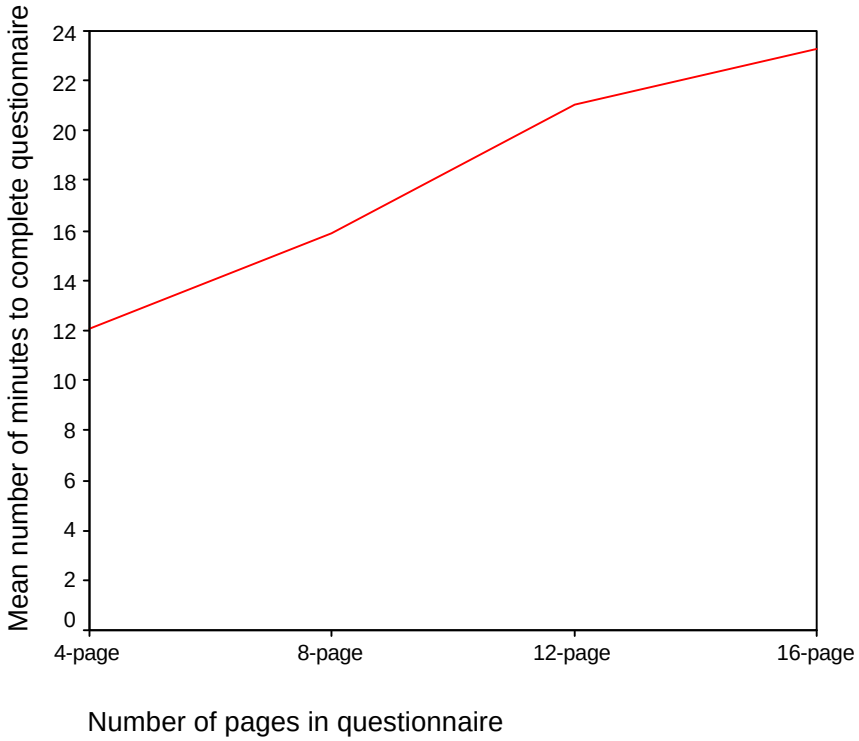
How long did it take you to complete the questionnaire?

Table 5 shows the reported mean number of minutes taken to complete each type of questionnaire. It can be seen that, as would be expected, the longer the questionnaire, the longer it took to complete it. However, the time taken does not increase in proportion to the number of pages in the questionnaire, suggesting the time taken to complete extra pages diminishes as more pages are added. This finding is illustrated in Figure 1. A one-way analysis of variance and post-hoc tests based on least squares differences confirms that there are significant differences in the mean lengths of time taken to complete each of the four types of questionnaire, except when comparing the 12- and 16-page questionnaires ($F=50.8$, $df=3, 1317$, $p<.001$). That is, there was no significant difference in the reported times taken to complete the 12-page and 16-page versions.

Table 5 – Mean time taken to complete the four questionnaires

Length of questionnaire	Time taken to complete questionnaire
4-page	12.1 min
8-page	15.9 min
12-page	21.1 min
16-page	23.2 min

Figure 1 – Mean minutes to complete - four versions of the questionnaire



Were any questions difficult to understand?

Table 6 shows the numbers and percentages of respondents who thought that one or more of the questions were difficult to understand. It can be seen that, for all four questionnaires, a very small minority (3.0% overall) of respondents reported any difficulty with understanding any of the questions. However, for the 12-page questionnaire, a greater proportion of respondents (5.3%) reported difficulty with some questions.

Table 6 - Were any questions difficult to understand?

Length of questionnaire	% reporting difficulty understanding questions
4-page	2.1
8-page	1.3
12-page	5.3
16-page	2.0
Mean overall	**3.0**

Table 7 shows the comments made about questions that were difficult to understand for each of the different lengths of questionnaire.

Table 7 - Comments about difficult-to-understand questions

Question Numbers	Subject of question	Comment
4-page questionnaire		
4	Were you ever bothered by noise at night?	It was not only one patient that could not be helped out the machinery
14	Did you want to be more involved in decisions about your care?	I couldn't answer yes or no. I didn't want to get involved because I had every confidence in the doctor's decision. But it was discussed thoroughly with me, and if I wasn't happy I could say. My consideration was always taken into account
17	Did staff ask name and address more often than you thought necessary?	Because when you go for op: they have to make sure no mistake with the patient and what they are going to do. Of course you think it is a lot but this helps to make sure no mistakes are being made.
24	Did staff discuss follow-up social services?	Too many people with information
29	Education	What has the age of my leaving school got to do with the care I received while in hospital
General		This sheet - I filled the form for my 88 year old mother who is deaf and almost blind with her given answers. What happens to all 80+ who has not got anyone
General		Only because I had help
Language		All. Because my English language is not good and I looking in the dictionary to find the meanings of the words and thinking to know how can answering out the questions
General		This sheet - I filled the form for my 88 year old mother who is deaf and almost blind with her given answers. What happens to all 80+ who has not got anyone

8-page questionnaire		
41-44	Leaving hospital	Difficult to answer as left this hospital to be transferred to another one
48		I was not aware that I could pick and choose which hospital to be treated in, therefore why would I recommend this hospital to others? i.e. only private patients can choose.
	General	Some of the questions answers were not broad enough in scope; you should leave an empty box for any other alternatives
12-page questionnaire		
A1, A4, A5	Admissions procedure	I was admitted from another hospital
B1	How many room or wards did you stay in?	I stayed in a ward with 8 beds. No room
B7-B8 H2-H11	Noise and "Leaving Hospital"	Difficult to answer
E2	“Did you want to be more involved…?	The question invites an incomprehensible answer. I was involved in decisions about my care. It was unnecessary to be more involved. Therefore answer is No.
E5	How much information about your condition or treatment was given to your family…?	Should have included the word "none"
E6	Did you find someone… to talk to about your concerns?	To what concerns does the question refer?
H5	Did a member of staff explain the purpose of medicines you were to take home…?	Repeat of medicines already being taken.
K3	Full time education.	
General		I had three hospital stays in sequence for the same condition
General		Most questions due to being in two hospitals, care was different in both
General		Some questions could be answered with an "in between" or with 2 or more ticks
General		Too complex
General		I'm 80 years of age and rather slow and I have to think. I‘m very forgetful.
16-page questionnaire		
Only one comment made in this section for 16-page questionnaire		
B11	Food quality	Whether the food is good-bad-adequate is conditional

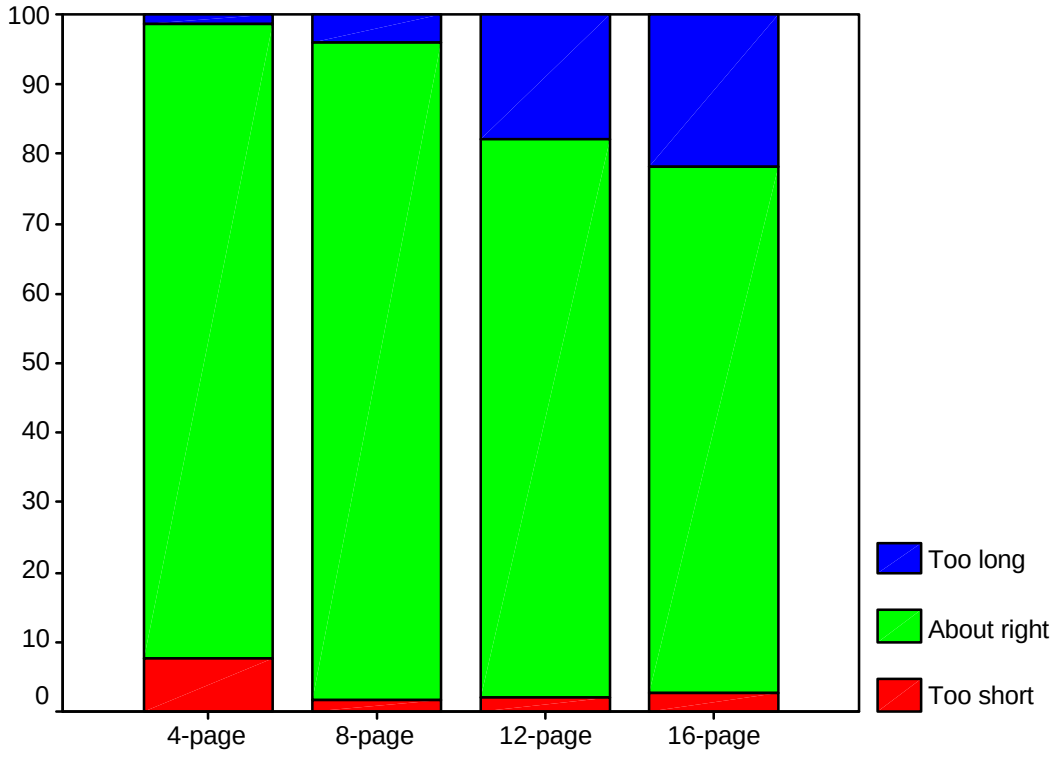
What did you think of the length of the questionnaire?

Table 8 and Figure 2 show the percentages and proportions of respondents who thought questionnaires were too long, about right or too short for each type. It can be seen that, for all four versions, a large majority of respondents thought it was about right. However, greater proportions thought that the shorter versions were too short and the longer versions were too long. In particular, 22% of patients thought the 16-page version was too long.

Table 8 – Evaluations of lengths of four types of questionnaire

	Pages in questionnaire			
	4	**8**	**12**	**16**
Too long	1.5%	3.9%	17.9%	22.0%
About right	90.1%	94.4%	80.3%	75.5%
Too short	7.6%	1.7%	1.9%	2.5%
Total	100%	100%	100%	100%

Figure 2 – Evaluations of length of questionnaire by four types



Were there any questions that you thought should not have been asked?

Table 9 shows the numbers and percentages of respondents who thought one or more questions should not have been asked. It can be seen that very few respondents (2.2% overall) thought that any questions should not have been asked.

Table 9 – Respondents who thought some questions should not have been asked

Length of questionnaire	Numbers - questions should not have been asked	%
4-page	14	3.0%
8-page	3	1.3%
12-page	10	2.3%
16-page	2	1.0%
Totals	**29**	**2.2%**

Table 10 shows the comments respondents made about questions they thought should not have been asked. It can be seen that the most frequent comments refer to questions about education and ethnicity. This is particularly evident for the 4-page questionnaire, perhaps because the proportion of questions that cover demographics is greater than for the longer questionnaires. Confidentiality concerns were also raised about the date-of-birth question.

Table 10 - Anything should not have been asked?

Question Numbers	Subject of question	Comment
4-page questionnaire		
9, 12, 16	Opportunity to discuss fears… with doctor / nurse / hospital staff?	All the same question really?
27, 28, 29, 30	"Your background"	Seem to be irrelevant to the rest of questionnaire
28	Date of birth	1916 ought to be OK
28	Date of birth	Personal
28	Date of birth	You might as well ask the persons name. This identifies the person. Just ask the age would be ok.
29	Education	No comment
29	Education	Not relevant for a stay in hospital.
29	Education	The answer to this will not improve the NHS.
30	Ethnicity	Hospital help is for everyone no matter what ethnicity. Too many surveys ask this question
30	Ethnicity	It's no business off anyone else what ethnic group I belong to
29	Ethnicity	What has the question 29 got to do with your hospital treatment

8-page questionnaire		
48	Would you recommend this hospital to your family and friends?	Reasons for not recommending...(maybe too personal)
50	Date of birth	Date of Birth and number plus pathology can identify a patient. In research they should be anonymous
51	Education	Not sure the reason for it
51	Education	I could not think the question was relevant to my inpatient at hospital
52	Ethnicity	What about Welsh and Scots and English being put on your list of ethnic groups or are we a dying breed
52	Ethnicity	You did not specify why this question need to be ask
General		There should be a note at the front of the form instructing patients that if they do not wish to answer a question they don't have to.
12-page questionnaire		
K2	Date of Birth	D.O.B.
D11	Did nurses know enough about your condition	I believe nurses should know what they are doing
E1	Did staff say different things?	If they work as a team they say the same thing
E8	Enough privacy while being treated?	Well, I have not been to any hospital where at least there no screen
E4 & 5	Did family get opportunity to talk to doctor? / How much information was given to family?	They do not allow for the possibility that I wanted to be aware of or to control the information my family and friends had, although I was happy for them to be informed. H10 similarly.
H10	Were family and friends given information on discharge?	As above
J2	How well did doctors and nurses work together?	I do not think I am qualified to judge and give a proper answer to this question
K2, K4	Education / ethnicity	Does it matter what ethnic group you are from
K4	Ethnicity	No need to know
General	(Green booklet is information about Aortic Aneurysm)	Some that need not have been posed if compiler had taken the trouble to investigate the excellent material freely available - See enclosed green booklet.
General		There are too many similar questions. Similar to each other repeated questions in some other form
16-page questionnaire		
K3	Education	What has education got to do with health?

Were there any questions that should have been included but were not?

A wide variety of additional questions were suggested. The table in Appendix C shows the suggestions made for additional questions and the types of questions suggested are summarised in Table 11 below. All topics for which there were 7 or more comments are included in the table, which indicates the numbers of respondents who made those comments for each version of the questionnaire. It can be seen that, in particular, respondents thought there should be more questions on equipment and facilities, waiting (both for admission and when in hospital), food and staffing levels.

It is interesting that many of these suggested additions were, in fact, already included in the questionnaires about which the patients were commenting. For example, there is at least one question in all four versions of the questionnaire on both food and waiting for admission, but these are the issues most commonly mentioned as not have been adequately covered.

Table 11 – Most frequent questions that should have been included

Subject	Number of pages in questionnaire				Totals
	4	8	12	16	
Equipment / Facilities	3	7	5	5	**20**
Waiting for admission	5	5	7	1	**18**
Waiting in hospital	8	2	6	1	**17**
Food	7	2	6	1	**16**
Staffing levels	4	7	1	0	**12**
Other staff	2	1	3	3	**9**
Follow-up care	2	3	3	1	**9**
Staff attitudes	1	3	4	0	**8**
Standard of care	2	1	2	3	**8**
Comfort / caring	4	2	2	0	**8**
Different wards / hospitals	1	1	5	1	**8**
Reason for admission	0	2	3	2	**7**
Success of treatment	1	1	5	0	**7**
Continuity of care	0	1	4	2	**7**
Totals	**40**	**38**	**56**	**20**	**154**

5 Concordance of responses in different versions

This section reports on the properties of an aggregate score derived from questionnaire: the 15-item Picker Patient Experience index (PPE-15).[11] The items that constitute this measure have been included in all versions of the questionnaire. As noted above, it is reasonable to make direct comparisons between the 4- and 12-page versions, and the 8- and 16-page versions, but comparisons of all four versions must be of a more speculative nature.

5.1 The PPE-15

Data derived from Picker surveys in five countries (UK, Germany, Sweden, Switzerland and USA) were used to examine how the individual questions performed against specific psychometric criteria (applicability to the majority of respondents, internal consistency reliability, correlation of the subset with the number of items indicated as 'problems' on the original measure, item to total correlations, replicability in each of the five country datasets).[11] This procedure resulted in the selection of 15 items which have been included in the PPE-15.

5.2 Comparison of index score (PPE-15) by length of questionnaire

The 95% confidence intervals on the mean scores for the PPE-15 index were calculated. They were found to overlap on the 4- and 12-page questionnaires, as they also did for the 8-and 16-page versions. Additionally, 95% confidence intervals of the means of the PPE-15 overlapped in almost every case on all questionnaires. These results suggest that similar results were detected for each type of questionnaire, and length of questionnaire does not have a significant influence on scores.

5.3 Internal reliability and item-total correlation

High levels of internal reliability provide greater confidence that a scale is both measuring a meaningful underlying unitary concept and is doing so accurately, thereby permitting comparison between, for example, NHS Trusts. Internal reliability is assessed by the alpha statistic with a score of 0.7 or higher being regarded as good. The PPE-15 passes this test for each form of the questionnaire, although it was lowest for the 16-page questionnaire. Similarly, it has been argued that items should correlate with the total index score at approximately 0.4 or above. This test was passed in most instances except in the 16-page version where two items fail this criterion, although not by a substantial margin.

5.4 Conclusions

Length of questionnaire has a limited effect on scores, psychometric properties, or levels of missing data on the PPE-15. There is some evidence to suggest that the 16-page questionnaire performed slightly less well, but the effect is unlikely to substantially alter results.

6 Identifying patients' priorities

For half of the Trust C sample, a different additional questionnaire was included with the mailed pilot Inpatient Questionnaires. These additional questionnaires were included with equal numbers of 8-page and 16-page questionnaires. That is, they were included with 375 of the 8-page questionnaires and 375 of the 16-page questionnaires. Of that total of 750 patients, 494 useable response sheets were returned, representing a response rate of 65.9%.

Respondents were asked to rate 30 aspects of inpatient care as "Most important" (1); "Quite important" (2) or "Least important" (3). The purpose of this research was to determine whether the mandatory questions covered by the Core Questionnaire are rated most important by patients.

Table 12 shows the mean ratings on each of the aspects of care in descending order of importance. The right-hand column shows the numbers of patients who rated each aspect of care as "Most important". It can be seen that there is a strong relationship between these two measures of importance in that the issues with the lowest mean ratings have the highest number of "Most important" ratings. The aspects of care that were rated most important were *Confidence and Trust in doctors and nurses treating me*; *Clear explanations of my condition or treatment* and *Staff knowing enough about my condition and treatment*. The issues rated least important were *Having access to my medical records*; *Clear information about ward routines* and *Invitation to visit the hospital and meet staff before admission*.

Table 12 - Mean ratings of 30 aspects of inpatient care

Aspect of care	Mean rating	Percentage who rated issue "Most important"
Confidence and trust in doctors and nurses treating me	1.05	93.1
Clear explanations of my condition or treatment	1.10	88.0
Staff knowing enough about my condition and treatment	1.13	85.2
Cleanliness of hospital	1.15	84.1
Getting clear answers to my questions	1.15	83.7
Being treated with dignity and respect	1.18	79.7
Pain relief	1.22	77.4
Operations or procedures being performed on time	1.24	74.6
Opportunity to talk to a doctor	1.27	72.4
Staff being open with me	1.27	71.3
Privacy when being examined or treated	1.30	70.1
Prompt help from hospital staff when I need it	1.33	65.9
Enough notice of operation or treatment cancellation	1.34	64.6
Being involved in decisions about my care	1.36	64.6
Information about medication	1.36	63.4
Not being discharged from hospital too early	1.37	65.2
Not waiting too long on a trolley or a chair before getting to ward	1.37	65.9
Short time on the waiting list before admission	1.43	57.5
Staff who understand my anxieties and fears	1.46	54.5
Information about my recovery at home	1.48	53.3
Being given an explanation about why I have to wait	1.49	54.5
Good quality food	1.64	43.5
Information about what to expect before admission to hospital	1.64	41.5
Not having to share a ward or room with patients of opposite sex	1.73	50.8
Not being moved around from ward to ward within the hospital	1.81	35.0
Low noise levels	1.82	32.5
Knowing the name of the staff in charge of my care	1.86	30.9
Having access to my medical records	1.98	28.9
Clear information about ward routines	2.00	22.6
Invitation to visit the hospital and meet staff before admission	2.39	11.0

7 Comparison of alternative ways of deriving ‘core’ questions

7.1 The PPE-15

The original ‘core’ questions, included in all four versions of the questionnaire, were derived from the PPE-15, described in section 5 (above). The problem scores derived from these questions were as follows:

1 Doctors' answers to questions not clear*
2 Nurses' answers to questions not clear*
3 Staff gave conflicting information*
4 Doctor didn't discuss anxieties or fears*
5 Doctors sometimes talked as if I wasn't there*
6 Not sufficiently involved in decisions about treatment and care*
7 Not always treated with respect and dignity*
8 Nurses didn't discuss anxieties and fears
9 Not easy to find someone to talk to about concerns
10 Staff did not do enough to control pain
11 Family didn't get opportunity to talk to doctor
12 Family not given information needed to help recovery
13 Purpose of medicines not explained
14 Not told about medication side effects
15 Not told about danger signals to look for at home

Not all items in the PPE-15 were applicable to all respondents, either because they did not report pain, because they did not have any family ties, or because they did not have any medications. Consequently, the PPE-15 was re-examined and seven items were selected which are appropriate to all respondents (PPE-7). Items included in the PPE-7 were those for which the data were most complete and which, when summed, were most highly correlated with the sum of the 15-item version. The PPE-7 items are indicated by an asterisk in the list above.

7.2 The rating exercise

Survey respondents were asked to indicate their perception of the relative importance of 30 different issues. They include most of the questionnaire items, although expressed in a slightly different form. The top fifteen were as follows:

1	Confidence and trust in doctors and nurses treating me
2	**Clear explanations of my condition or treatment****
3	Staff knowing enough about my condition or treatment
4	**Cleanliness of hospital**
5	**Getting clear answers to my questions****
6	**Being treated with dignity and respect****
7	**Pain relief****
8	**Operations and procedures being performed on time**
9	Opportunity to talk to a doctor**
10	Staff being open with me
11	**Privacy when being examined or treated**
12	Prompt help from hospital staff when I need it
13	**Enough notice of operation or treatment cancellation**
14	**Being involved in decisions about my care****
15	**Information about medication****

Items which appear in both lists are marked with a double asterisk. Items currently included in the 8-page Core Questionnaire are indicated in bold. All the above items are included in the longer 12-page and 16-page versions.

8 Conclusions and recommendations

8.1 Questionnaire development and validation

The qualitative research did not identify any important items missing from the original Picker questionnaires and they performed well in the cognitive testing. Most of the suggestions made by patients responding to the *What do you think of the inpatient questionnaire?* survey were already covered in the questionnaire, albeit sometimes in a less detailed form. Several people suggested including questions about equipment, which is not currently covered in this questionnaire, but is relevant to the estates and facilities survey being carried out by NHS Estates.

The questions (in all four versions) seemed to be acceptable to most respondents. Item response rates (a reasonable measure of acceptability and comprehensibility) were high in most cases. The demographic questions (education and ethnicity) performed slightly less well in this respect, but this is a common experience in surveys of this type.

A few minor modifications were made to the questionnaire design and wording to iron out the problems which emerged during the first pilot phase. The original 4-page Core Questionnaire included the PPE-15 questions plus some essential 'filter' questions, a basic health status question and demographic questions. A question was added to identify patients who had to wait on trolleys in A&E departments, to accommodate a DH priority. The decision to introduce a longer 'ethnic' question and the EQ5-D health status measure led to the eventual abandonment of the 4-page version of the questionnaire because these questions took up too much space to be included in four pages.

It is important to stress that the development of these questionnaires has involved very large numbers of patients, starting with the original research carried out by the Picker Institute in the USA, followed up with qualitative and quantitative research involving many British patients to derive the UK version of the Picker questionnaire, and subsequently the research reported here. We are confident that these questionnaires cover topics that are considered important by British patients and extensive testing has demonstrated the validity of the instruments and the salience of the topics included.

8.2 Questionnaire length

The variation in response rates among the four different versions was not very great, suggesting that questionnaire length does not have a strong effect on patients' willingness to return questionnaires. For all types of questionnaire, the response rate was at least 60% - the target set by DH for the Acute Trust Surveys. There was a small effect on data completeness as questionnaires got longer in that there tended to be a higher proportion of missing responses among the longer questionnaires.

The shortest version in use in the Acute Trust survey programme is the 8-page Core Questionnaire. Trusts wanting to use a longer questionnaire can be confident that they should be able to achieve an acceptable response rate with either the 12-page or 16-page versions.

8.3 Selection of performance indicators

It is not surprising that patients' priorities concerned a wide variety of issues. However, one of the strongest themes that emerged from the prioritisation exercise was the desire for clear and accurate information about their illness and treatment. This seems closely related to the importance accorded by patients to trust in the staff who look after them, the sense that staff are knowledgeable, and the desire for greater involvement in decisions. It is interesting to note that cleanliness of the ward and bathroom facilities, another high priority, seems to be unrelated to these other issues. However, the analysis of the focus group discussions suggested that this issue is often associated with anxieties about hospital-acquired infections. This is consistent with the general importance placed on high standards of clinical care.

Two approaches to selection of performance indicators were considered:

a) selecting items which passed various pre-defined psychometric tests;

b) selecting items which patients considered to be the most important.

In addition we considered and tested (reported separately) the creation of an overall index score, which could be used to rank hospitals. We do not recommend this latter approach. Instead we think a combination of a) and b) produces a list of items that have a clear defensible rationale and can therefore be defended (see list of recommended items in section 7.3). The topics also fit well with the government's commitments outlined in the *NHS Plan*.

8.4 Pilot survey results

Overall, the pilot survey results at the three Trusts reveal high problem scores for some key areas. These scores are generally worse than the results obtained using the same Picker questionnaires in other countries (Germany, Sweden, Switzerland and the USA).[10]

There were significant differences between the Trusts in 11 of the 20 questions on which the Trust's problem scores were compared. These comparisons were not adjusted for possible confounding variables such as age, sex, ethnicity or health status, but our analysis of the CHD data suggests this would not make much difference to the scores for individual Trusts.[12]

It is important to remember that the problem scores derived from these questionnaires reflect patients' subjective impressions of their experience. As such, they provide important indicators of the patient's experience, but they need careful interpretation. For example, a 'no' response to the question *Was there one doctor in overall charge of your care?* does not necessarily mean that no one was in charge, but simply that the patient was not aware of who was in charge. Our qualitative research has indicated that many patients are uncomfortable with not knowing who is in charge of their care. One Trust, on seeing their patients' responses to this question, decided to provide staff with business cards to hand to patients so that they knew the name of the person who was supposed to be coordinating their care.

The main value of this approach to gaining patient feedback is to gather detailed information for use by health care providers in setting priorities for change; in other words a 'bottom up' approach to quality improvement. In our experience this type of feedback can be very useful for helping staff to see things through the patients' eyes and stimulating them to initiate changes in the way care is delivered to patients. The surveys can also contribute to external monitoring and national performance assessment, but this should not be seen as their prime purpose.

8.5 Recommendations for the next round of surveys

The results of these pilots suggest that each of the four types of questionnaire is acceptable to a very large majority of inpatients, that they are all capable of yielding a response rate of at least 60% and that the proportion of missing responses in each questionnaire is low on all versions of the questionnaire, although it is higher for the longer ones. The ratings of the importance of issues to patients suggest that all the topics that are most important to patients are adequately covered in the 8-page questionnaire (and consequently in the 16-page questionnaire). A number of minor modifications should be considered before going ahead with the 2002/3 Acute Trust Surveys.

- Revert to the original 3-response-option *Emergency* / *Planned admission* / *Something else* question, or consider a further revision of the question.

- Reduce the number of questions in the Core Questionnaire in order to allow Trusts greater flexibility to include questions that reflect their own policy priorities.

- Remove from the Core Questionnaire questions that relate to issues that were rated at not important in the rating exercise. (For example, the question on *Being asked name and address too often* was not given high importance by many patients.)

References

1. Gerteis M, Edgman-Levitan S, Daley J, Delbanco T L (eds) Through the patient's eyes. San Francisco: Jossey-Bass, 1993
2. Cleary P D, Edgman-Levitan S, Walker J D, Gerteis M, Delbanco T. Using patient reports to improve medical care: a preliminary report from 10 hospitals. Quality Management in Health Care 1993; 2: 31-38
3. Cleary PD, Edgman-Levitan S, Roberts M, Moloney TW, McMullen W, Walker JD, Delbanco TL. Patients evaluate their hospital care: A national survey. Health Affairs, 1991; 10(4):254-267.
4. Cleary P D, Edgman-Levitan S, McMullen W, Delbanco T L. The relationship between reported problems and patient summary evaluations of hospital care. Quality Review Bulletin 1992; Feb: 53-59.
5. Bruster S, Jarman B, Bosanquet N, Weston D, Erens B, Delbanco T L. National survey of hospital patients. British Medical Journal 1994; 309: 1542-9
6. Wedderburn Tate C, Bruster S, Broadley K, Maxwell E, Stevens L. What do patients really think? Health Service Journal 12th January, 1995: 18-20
7. Cleary PD, Edgman-Levitan S. Health care quality. Incorporating consumer perspectives. JAMA. 1997;278:1608-12.
8. Coulter A, Cleary P D. Patients' experiences with hospital care in five countries. Health Affairs 2001, 20 (3), 244-252
9. Coulter A. Quality of hospital care: measuring patients' experiences. Proceedings of the Royal College of Physicians of Edinburgh 2001; 31 (suppl. no. 9): 34-36
10. Coulter A. Quality of hospital care: which patients get the worst deal? OECD Observer Nov 2002
11. Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience questionnaire (PPE-15): tests of data quality, validity and reliability using data from in-patient surveys in five countries. [submitted for publication, 2001]
12. Jenkinson C, Coulter A, Bruster S, Chandola T, Jones P. Factors accounting for patients' experiences of hospital care: an analysis of the National Survey of NHS Patients - Coronary Heart Disease. [submitted for publication, 2002]

APPENDIX A – Focus group topic guide

Preparation

Arrange the chairs for all the participants and the moderator at a round table. Ensure the recording equipment is in working order. Remind people in neighbouring offices that a discussion group is taking place and ask them not to make too much noise. As participants arrive, ask them to write their name on a sticky label and attach it to their person. Remember to check the tape recorder regularly to ensure it is recording properly and to turn the tape over after 60 minutes.

Introduction (10-15 minutes)

- Moderator introduces herself and welcomes everyone to the group
- Explain that the aim of the discussion group is to find out about experiences of being an inpatient in an NHS hospital.
- Emphasise that each participant should feel free to tell his or her own personal story, and to talk about what is important to them.
- The group will last for two hours
- The discussion will be led by the researcher, and will focus on several topics relating to inpatient experiences
- Location of toilets and fire exits
- **Tape recording**: Explain that the discussion will be tape recorded to ease later analysis. Say that nobody will be identified individually, all comments will be anonymised and personal details will be removed from the transcripts.

Warm up exercise (10-15 minutes).

- Moderator asks each individual their name and where they have come from. Also, what motivated them to want to come and share their inpatient experiences in a discussion group.
- Participants are asked to turn to the person next to them and briefly tell them which hospital they were recently admitted to. Also tell that person one good thing about the hospital stay and one not so good thing about the hospital stay.
- Individuals are then asked to tell their story to the group using the following themed discussion prompts:

Themed discussion (60 minutes)

Admissions

- How were you admitted – A&E or planned?
- If planned how much notice were you given of your admission?
- Was the admission cancelled?
- How was it cancelled by phone or by letter?
- How much notice were you given of the cancellation?
- How many times was it cancelled?
- What reasons were given for the cancellation?
- How organised was the care you received in A&E?
- How long were you kept waiting in A&E before you were seen by hospital staff?

Trolley waits

- When you were waiting in A&E were you waiting in a chair, a trolley or something else?
- Were you waiting in a corridor or a cubicle?
- Could you get assistance if you needed it?
- Did you wait on a trolley at any time after you had been admitted?
- Did a member of staff explain how long you would have to wait in A&E?
- Did you feel cared for while you were waiting?

Written information prior to admission

- Before your admission to hospital were you provided with any information about the hospital?
- What sort of information were you given?
- Was it about the hospital, about your condition and treatment or both?
- Was the information clear and easy to understand?
- What sort of information would you have liked to get?
- Were you invited to visit the hospital prior to admission?

- Would you have liked to visit the hospital prior to admission?

Hospital and ward rules

- Before you were admitted to hospital did anybody tell you about the rules of the hospital?
- Before you were admitted to hospital were you given a set of written rules?
- Were you informed about visiting times?
- Were you told when meals would be served?
- What kind of rules were you aware of during your admission?

Card Sort Exercise (20 minutes)

- Participants are given 30 cards, on which issues relating to the inpatient experience are written. The following is a list of the items on the cards:

Card sort items

1. Short time on the waiting list before admission
2. Not having to wait too long on a trolley or a chair in casualty
3. Enough notice of operation or treatment cancellation
4. Information about what to expect before being admitted to hospital
5. Invitation to visit the hospital and meet the staff before admission
6. Being given an explanation about why you have to wait
7. Not being moved around from ward to ward within the hospital
8. Clear information about ward routines
9. Not having to share a ward or room with patients of the opposite sex
10. Low noise levels
11. Cleanliness of hospital
12. Staff who understand your anxieties and fears
13. Good food
14. Clear explanations of your condition or treatment
15. Knowing the name of the staff in charge of your care
16. Opportunity to talk to the doctor
17. Getting clear answers to your questions
18. Staff being open with you
19. Staff knowing enough about your condition and treatment
20. Confidence and trust in doctors and nurses treating you
21. Operations or procedures being performed on time
22. Privacy when being examined or treated
23. Pain relief
24. Not being discharged from hospital too early
25. Information about your recovery at home
26. Being treated with dignity and respect
27. Prompt help from hospital staff when you need it
28. Information about medications
29. Having access to your medical records

30. Being involved in decisions about your care

- Participants are asked to sort the cards into three piles:
    - Most Important
    - Quite Important
    - Least Important
- Discussion: Why are those items important? Ask participants to talk about their most important items, and to identify one item as the most important issue.

Closure

- Thank all participants very much for taking part in the focus group. Reassure them that everything that they have shared today will be treated as confidential. Emphasise how valuable their contribution is as a means of informing NHS policy. Ask them how they feel about having shared their experiences with others.
- Ask them if they have any further questions.
- End the meeting. Switch off the tape recorder and label the tape with name and date and time of recording. Arrange dispatch to transcribers.
- Hand out gift vouchers to each participant. Arrange payment of travel expenses.

APPENDIX B - Questions that should have been included but were not

Pages	Subject	Comment
4	Access to doctors	A question should have been asked about access to doctors. My wife wanted to see a doctor to ask about my condition and progress and no one could locate a doctor (3 sisters, 2 from ENT and one from dialysis) tried to find a doctor to enable her to ask questions but could not find one.
4	Access to doctors	Did I see a doctor at all during my stay? NO. Nurses did it all
8	Access to doctors	Were you seen by a consultant?
16	Access to doctors	Did you see a doctor before discharge. No.
4	Access to hospital	Access to hospital / ward
16	Access to hospital	Family visiting - 40 miles journey. No help given (I was OK with family cabs). What if no car?
8	Admission procedure	Too many forms filled in on arrival
8	Admission procedure	Reception
16	Admission procedure	Admissions: Bed management
4	Answering bells	When ringing an emergency bell for assistance it's important that it's answered, instead of me hearing the nurses etc. chatting about what they're doing at the weekend. That day I passed out in the bathroom. Could have been worse.
4	Answering bells	The nurse 'call' button worked, but nurses took 5 minutes or so to respond.
8	Answering bells	How long left on commode, bed pan.
8	Answering bells	You should ask if when calling for help or assistance did a nurse come to your aid? How long before you received help or acknowledgement?
12	Answering bells	I was very unwell at some stage of my visit and had to walk down the corridor to get help as my bell didn't work whilst I was there
12	Boredom	Ways of relieving boredom in hospital
12	Boredom	Were any reading materials available.
16	Boredom	Hospital entertainment - TV, books etc?
4	Cleanliness / infection control	1) More questions about cleanliness and hygiene. 2) Ask patients if they would like to have MATRONS reintroduced to hospitals
4	Cleanliness / infection control	Assistant in pre-ops didn't wear gloves. Pre-ops room was utterly filthy. General opinion. Jug of urine left in Ladies all the time I was there - disgusting
4	Cleanliness / infection control	Cleanliness.
8	Cleanliness / infection control	Did the staff observe good barrier nursing practice?
8	Cleanliness / infection control	Questions cleaning of wards & toilets
12	Cleanliness / infection control	There should have been a space by QB9 and B10 to explain why I thought toilets and ward were only fairly clean.
4	Comfort / caring	Evening of op had to make my own bed.
4	Comfort / caring	I was not just a number was I?

Pages	Subject	Comment
4	Comfort / caring	More patient comfort questions
4	Comfort / caring	One of the questions should was your time in hospital comfortable
8	Comfort / caring	Did staff (nurses and doctors) come back in the time scales they said they would
8	Comfort / caring	I feel a question should have been asked in relation to whether or not a holistic approach was taken towards the patient care provided.
12	Comfort / caring	During your stay in hospital did doctors, nurses or staff seem to address your mental or psychological welfare? (One heals the whole person, not the organ!)
12	Comfort / caring	Whether the patient felt listened to, by members of staff
4	Comments box on questionnaire	Allow more space for personal comment
4	Comments box on questionnaire	Some questions can not be answered by a yes or no.
8	Comments box on questionnaire	A box like that for other comments might be useful for qualifying remarks if required against certain ticked answers.
8	Comments box on questionnaire	Comments box could have been longer. I feel you can learn more from comments than from tick box questions. There was a lot more favourable information that I could have included had I had the space
16	Comments box on questionnaire	Each question should have a comment box under
8	Continuity of care	Were the same examinations and tests (e.g. scans, x rays etc) given by different doctors?
12	Continuity of care	I found that the ward was not expecting me when I was brought up from A & E
12	Continuity of care	Whether a patient got to see the same doctor each time
12	Continuity of care	Yes there was NO continuity in my care-never the same nurse etc. twice
12	Continuity of care	You're passed on from one [doctor] to another.
16	Continuity of care	Amount of doctors seen by
16	Continuity of care	It would have been reassuring to know which doctor and which member of the Nursing staff were in overall charge of my care.
8	Courtesy	Lack of enquiries regarding senior medical staff i.e. surgeons- including bedside manner and post operative discussions
12	Courtesy	No mention of the use of first names vs Mr or Mrs. No mention of the attitude of staff to patients: rude, surly etc.
12	Diabetes	Are you diabetic and all the questions appertaining to
12	Diabetes	I am diabetic there was no questions on diabetic food no diabetic food on offer, if you were able to eat it you had it if not you went without.
16	Diabetes	A question on the standard of diabetic management / competence would obviate half of my p.16 comments
12	Different staff	More specific about the staff who were helpful / incompetent - some were very good and some very poor
16	Different staff	I found that it was difficult as the questions about doctors

Pages	Subject	Comment
		and nurses was a general question. And i had different opinions on those on the ward to those at A&E.
16	Different staff	Name of the nurse that looked after me and name of hospital
4	Different wards / hospitals	If you had to be moved from one ward to another e.g. C.C.U. to normal ward. What was the difference in treatment like.
8	Different wards / hospitals	Means to report on the very different performance & experience in different types of wards
12	Different wards / hospitals	Standards of care differed in the hospital. Different areas, i.e. A & E Wards, etc. Some of your questions did not take this into account.
12	Different wards / hospitals	Although I was admitted first to one hospital and then after a period of time and for further treatment I was transferred to another hospital. The questions referred to just the one hospital.
12	Different wards / hospitals	Comparison between wards when moved around. Answer would have differed
12	Different wards / hospitals	It would have helped to be able to answer for the different wards I was in.
12	Different wards / hospitals	Which hospital?
16	Different wards / hospitals	No but many questions were not answered properly, for example the care I received in accident and emergency was very different from that in the ward.
4	Discharge arrangements	Discharge from hospital - taxi arrangements. No seating in taxi waiting area chair requested was told by porter? In nearby office-'nothing to do with me, write to complaints'. Not a helpful reply after stomach bleed.
4	Discharge arrangements	Yes, about being discharged and the way nursing staff treat you on that day is a disgrace. Both of these hospitals.
4	Discharge timing	Delaying my discharge
4	Discharge timing	Only that one could stay or prefer to stay 4-5 days. Instead of in one day, operated on the next day and out discharged the next day.
8	Discharge timing	80% of patients I came into touch with were awaiting transfer to another hospital. As you can appreciate that was the major question for all of us
16	Discharge timing	Do you think you should have been discharged
4	Equipment / Facilities	A question about the beds perhaps?
4	Equipment / Facilities	Facilities needed, viz : Plugs for baths & washbasins, Hooks for clothes etc in bathrooms & examination room / cubicle, Mirrors, Shelves for sponge bags in bathrooms etc. Minor maintenance. To unblock drainpipe from washbasin - make good old screw holes, etc. would help appearance. (full time odd job man)!
4	Equipment / Facilities	The beds were OK, but the bed "handset" in [Trust A] was hopeless. There were no headphones, only London Live was clearly audible through the hole that headphones should plug into. And that radio station is absolute talk all day.
8	Equipment / Facilities	Were the non-medical facilities available (i.e. library service) 1.Useful 2.Not useful 3.I did not know there was

Pages	Subject	Comment
		one 4.I did not need any such facilities
8	Equipment/Facilities	Access to a common room.
8	Equipment/Facilities	Condition of equipment in the hospital.
8	Equipment/Facilities	Condition of the hospital and equipment
8	Equipment/Facilities	Equipment being used by staff malfunctioned frequently. The staff managed very well with faulty equipment and were always cheerful and good tempered (e.g. blood pressure & temperature calculating machines)
8	Equipment/facilities	The need for tea making facilities for patients.
8	Equipment/Facilities	1. About the general fabric of the building other than the particular ward I was on. 2. Accessibility i.e. Parking, Transport etc.
12	Equipment/Facilities	If you are disabled could the hospital cope with your disability. Was the hospital furniture suitable for elderly patients.
12	Equipment/Facilities	Maybe things about installations, room, beds, facilities
12	Equipment/Facilities	There should have been questions concerning the amount, quality and age of equipment available to the staff.
12	Equipment/Facilities	Washing facilities
12	Equipment/Facilities	Would you liked to have been provided with the use of a TV
16	Equipment/Facilities	Questions about the running and lack of basic equipment
16	Equipment/Facilities	Was your locker space adequate?
16	Equipment/Facilities	Were there enough and desirable, wash rooms
16	Equipment/Facilities	Was your bed comfortable?
16	Equipment/Facilities	Would you like to have any other facility/service in the ward e.g. baby changing room for visitors etc.?
4	Follow-up care	A question with regard to any aftercare that was necessary.
4	Follow-up care	I only had a short stay in hospital, but the aftercare I had from the Intermediate Care Team who come to your home after you come home from hospital was excellent (only a few boroughs do this service, I know)
8	Follow-up care	After care- e.g. Follow-up appointments and tests should be arranged before you (in-patient) leave hospital.
8	Follow-up care	Follow-up after returning home by GP/Hospital.
8	Follow-up care	Questions on any follow up after discharge.
12	Follow-up care	Follow up care - what if problem is still there but no explanations why.
12	Follow-up care	Follow up dates.
12	Follow-up care	1.Post operative care 2. Follow up with G.P. 3. G.P. should contact the patient and explain the precautions to be taken and new medicine advice.
16	Follow-up care	No follow-up to GP
4	Food	Flexibility in obtaining food. It was not good
4	Food	Food
4	Food	Food: should be appetizing and attractively presented. Fish peas, and mash does not fill requirement. Rejected food not cost-effective. Bring back catering staff.
4	Food	Food: when you are sitting around all day the highlight becomes the next meal, choice, size, hot.
4	Food	I think the food issue is quite important and inadequate diet does not aid a speedy recovery. Which is the common goal.

Pages	Subject	Comment
4	Food	Nurses were wonderful. Food is awful
4	Food	Should have asked more questions on the food side
8	Food	Dietary requirements
8	Food	The Food Question. The standard of food and what could be done in future was not asked.
12	Food	Also a question about choice of food.
12	Food	Also more questions about the food (which was terrible).
12	Food	Choice of diet i.e. Coeliac + vegetarian
12	Food	Choice of food and selection and distribution of food.
12	Food	Food was not mentioned
12	Food	More time on the food to be talked about
16	Food	Not enough on quality and quantity of food
4	General about questionnaire	It is now 7 weeks since I was discharged and my memory of the time in hospital is beginning to fade. There may have been some things that bothered me at the time but I do not recall them now.
8	General about questionnaire	As stated above, no concern for wheelchair disabled as some questions could be answered in a different manner; although the treatment would be the same.
8	General about questionnaire	I had some difficulty in completing the questionnaire mainly because I initially was admitted on a planned joint replacement ward I suffered complications and in the next 6/7 days
16	General about questionnaire	Eye sight should be put in questionnaire.
8	GP	Have you ever felt perhaps that your GP's diagnosis was wrong thus delay to seeing the consultant?
4	Improvements to hospital	There should be a system for complaint about staff and conditions on each stay. This procedure should be quick, easy and confidential. You should have to fill in a form on each stay. Naming and shaming staff.
12	Improvements to hospital	In your opinion how can we improve our service/hospital for your stay
12	Improvements to hospital	What could have been done to improve the services and all the bad things/ experience the patient has been through and how to improve it
4	Information	What caused your condition, were you ever told
4	Information	Whether my hernia would recur. Little worried about that.
8	Information	Advice and help after discharge. Answering any questions concerning convalescence.
8	Information	Question is needed on expansion and explanation
12	Information	Following E1, you could have asked something about the impact of different information.
12	Information	I found I have had complications, which I was not informed about. Also post-op appointment 3 months later not 6 weeks due to no appointments
4	Language/ethnicity	I can't explain without interpreter. Sorry about that.
4	Language/ethnicity	My mother and myself often found doctors and nurses could not speak the Queen's English therefore we could not understand. My mother is 88 years and I am 62 years
8	Language/ethnicity	Nationality of staff in the hospital.
8	Language/ethnicity	Yes- some nurses could not speak or understand English.
12	Language/ethnicity	Anything to do with needs of ethnicity, cultural etc.

Pages	Subject	Comment
8	Length of stay	Length of stay
12	Length of stay	How long were you in for?
12	Length of stay	The length of stay in hospital
16	Length of stay	How long your stay was in hospital
16	Length of stay	I think it should ask about length of stay as obviously being in for one night does not qualify you to be very knowledgeable about the running of the place with any great accuracy
12	Medical notes	Regards one's personal notes whilst in hospital: refuses to take medicine if one is unable to for some reason. I think it is very unfair to make such remarks.
12	Medical notes	Whether notes / results etc. were ever lost / mislaid
4	Medications	I don't think questionnaires of this type give a true picture because the questions cannot be answered by a tick, e.g. No 13, my answer is Yes once, but it was really important (medication) difference and I had to fight to get it sorted.
4	Medications	It should have been written about, persons (like me) who cannot sleep, and the amount of tablets for this. I was given one tablet I did not sleep any night?
8	Medications	About medication (terminology),
8	Medications	Did you receive medication / treatment on time?
12	Medications	Drug distribution not mentioned (from Trolley)
4	Miscellaneous	[Trust A] needs a complete overhaul.
4	Miscellaneous	Theatre arranged for 9 - sent back to ward as time had changed to 9.30.
4	Miscellaneous	Too many to mention
12	Miscellaneous	Q. Do you think there is political interference in clinical judgment? A. Yes
16	Miscellaneous	Do you feel hospital managers support their staff?
16	Miscellaneous	No but a N / A alternative would have been better Qs E16 & 17
16	Miscellaneous	Whether respondent is local resident or a visitor?
4	Mixed sex ward	Opinions about being placed in a mixed ward.
8	Mixed sex ward	The question of mixed wards are important. Most patients don't like it.
4	Negative about questionnaire	I completed the questions on behalf of my mother who is 100 and would be grateful if you did not write to her again and she became very distressed and did not wish to answer the questions.
8	Negative about questionnaire	The questionnaire fails to offer answers that are realistic many questions did not an answer suitable for me to tick.
8	Negative about questionnaire	Not enough depth to questions and therefore will miss fundamental errors in hospital care
8	Negative about questionnaire	Now we have a questionnaire about the questionnaire
8	Negative about questionnaire	Poor warding (sic) e.g. Q48 gives you a chance to be glaringly positive but not to say 'not on your nellie'. This kind of error discredits the whole thing really.
12	Negative about questionnaire	Considering this is voluntary. I have had no end of reminders and 3 surveys to fill in. What a waste of money.
16	Negative about questionnaire	Too many questions should have been asked. Not enough room to tell you all of them.
16	Negative about	1.The questions are too simplistic. 2.The groupings make

Pages	Subject	Comment
	questionnaire	too many assumptions. 3.Try asking people what they really feel.
4	Number of admissions	How many times in the past 6 months have you stayed in hospital? This is because I've been in 3 times, therefore I've given an estimate on all 3
12	Number of admissions	How many times have you been in hospital.
12	Number of admissions	The answers to these questions are based on one day and a night in hospital to have a pacemaker fitted. On previous occasions I have always found the staff most helpful at [Trust A]
8	Nursing care	Questions about nursing care
8	Other patients	Did you have problems with any other patient.
4	Other staff	Questions regarding agency nurses.
4	Other staff	Perhaps one or two questions relating to pre-theatre and theatre staff?
8	Other staff	Comment on areas such as occupational therapists, Physio staff, X-Ray dept,
12	Other staff	No questioning of attitudes of ancillary staff and treatment unit staff.
12	Other staff	The availability of porters when you needed them could be very poor especially for outpatients at [Trust A].
12	Other staff	There was no mention of porters, treatment prior to entry to operation theatre and transfer back to ward
16	Other staff	Questions relating to care provided by other healthcare professions e.g. professions allied to medicine, radiographers and physiotherapists and midwifes.
16	Other staff	Questions relating to physio staff
16	Other staff	What about nursing auxiliaries? The care they offer is essential - they are like nurses who will give you a few extra minutes to talk over worries, or give advice if you want it. Hats off to them!
8	Overall	Why not ask: Did you feel that the hospital had done its best to treat your needs? Also: Would you feel confident about going back into the same hospital?
4	Pain	Being allowed to have more pain-killers rather than a stigma being attached because a year or so ago I had been a drug addict. I did not always agree with the drugs I was being given.
12	Pain	I experienced pain for seconds only on 2 occasions. I would have liked to be able to say no real pain.
12	Pain	Time taken to give pain relief
16	Pain	Pain management question did not take into account if you were on Morphine pain relief or taking your own medication as you began to recover, as I was.
4	Parking	Parking - People in outlying district of Surrey W Sussex pay enough to get to [Trust A], then have parking problems. I myself was clamped, but a letter got me a grateful refund. A special sticker could be used for a reasonable fee
8	Parking	Accessibility i.e. Parking, Transport etc.
16	Parking	Parking
4	Patient's state of health	Yes. Was the treatment available for the mentally handicapped good enough? No. Special expertise was

Pages	Subject	Comment
		totally lacking however nursing staff did their very best and were also understaffed.
8	Patient's state of health	About personal fears and circumstances
8	Patient's state of health	Are you still receiving hospital treatment? Daily, weekly, monthly?
12	Patient's state of health	Are you still concerned about your condition
12	Patient's state of health	Mental state.
16	Patient's state of health	All based on physical health not really enough on mental health.
4	Positive about care	None. Only to thank staff and nurses who looked after me when I had my operation.
4	Positive about care	Overall, of the hospitals I've been in, Kingston hospital comes up trumps. Very good hospital, no complaints whatsoever.
8	Positive about care	I was very satisfied in every way!
8	Positive about care	There was from time to time a definite shortage of staff. This was overcome by in several instances a member of the staff coming in on her day off for my sole benefit with the Chemo-therapy. Wonderful!
8	Positive about questionnaire	No I think the questionnaire was well presented and asked on all aspects of my stay.
12	Positive about questionnaire	As soon as I opened the envelope I started to fill it out as I wanted to share my experiences desperately. Thanks for sending it.
16	Positive about questionnaire	No - All questions were of the correct type to obtain maximum information in my case
4	Privacy / Confidentiality	1) Doctors / nurses automatically talking to family members without patient's consent. 2) Medical / health staff discussing conditions etc so close to other patients - lack of confidentiality
4	Privacy / Confidentiality	Lack of privacy whilst talking to doctors / medical staff
12	Privacy / Confidentiality	Yes, women would prefer privacy and female doctors to examine them
16	Private care	Were you offered private care for your stay in hospital?
8	Reason for admission	What were you in hospital for? It may help with understanding my answers.
8	Reason for admission	Why were you in hospital as all cases are different.
12	Reason for admission	What illness was.
12	Reason for admission	Did not ask questions about operations and seriousness of it.
12	Reason for admission	-The nature of complain / illness being treated
16	Reason for admission	Yes, why I was in hospital, what problem I had. Just so you do not have to cross reference with files. And how long so no one will get into trouble when found I never ate.
16	Reason for admission	What were you in for - as some questions were not always relevant.
8	Relatives	Ask how your wife / husband were treated. Most of the time it is with no respect at all, and they are usually the main carer.
12	Repetition	Time was wasted by repetition. Several different members of staff kept asking me the same questions.
4	Right ward	About the ward you were in. I had a throat problem, but was put in a Gynaecological ward, which wasn't right!

Pages	Subject	Comment
4	Right ward	Questions regarding specialist wards -i.e. did you go onto a ward that your doctors were there?
4	Right ward	Was I on the right ward to receive the right care.
8	Right ward	Were you on a suitable ward?
16	Right ward	Yes about mixing patients with totally different conditions
8	Safety	About a particular dangerous situation (being in bath alone), about particular friendly staff, about personal fears and circumstances
8	Safety	Were any mistakes made that were later ignored?
12	Security	A greater measure of security of patients' property when being moved. I lost all my shaving gear including tooth paste and brush also pyjama jacket
4	Staff attitudes	Attitudes of doctors to patients
8	Staff attitudes	Attitude of consultant/surgeons and anaesthetist towards patient - plus going through the operation procedures
8	Staff attitudes	Did doctors listen to you before deciding on admission. Only you know your own body.
8	Staff attitudes	Yes how helpful the staff were and there attitude to patients
12	Staff attitudes	Communication skills of doctors. Attitude of doctors/nurses
12	Staff attitudes	Nothing about the affection given so freely. I still remember my stay with gratitude and affection about that above all else, making one's mind at rest.
12	Staff attitudes	Staff appeared quite casual, not realizing that patients go into hospital with a lot at stake
12	Staff attitudes	The kindness of all the staff on C-3. They were very good to me I was in a lot of pain they helped me.
4	Staffing levels	About staffing levels, which were very poor at times and more detailed information regarding care practice especially for older people like myself.
4	Staffing levels	For me it was a concern to see doctors and nurses under such pressure. One hesitated to ask for assistance when staff were already fully engaged. A suitable question might cover this aspect
4	Staffing levels	If I had time I could write about Selly Oak. I think I am not the only one as everyone you spoke to said the same. The A&E ward the staff are run off their feet.
4	Staffing levels	One thing that became apparent was that many more nurses were needed in busy wards. They work long hours and get tired
8	Staffing levels	Did you feel other patients had the care and attention they needed?
8	Staffing levels	Did you feel there were enough staff on duty to care for you whilst you were an inpatient?
8	Staffing levels	Enough staff available.
8	Staffing levels	How long patients in single rooms are left completely to themselves without any contact with any hospital staff
8	Staffing levels	I believe the Swindon hospital was understaffed and as a result of this the staff was overworked.
8	Staffing levels	Was the nursing care adequate. Answer NO.Simply because there was too much for them to do, or sometimes nobody in charge, so auxillaries especially would become

Pages	Subject	Comment
		preoccupied with tasks not as urgent as the care of the patients
8	Staffing levels	Yes! What do you think of staffing levels at hospital?
12	Staffing levels	How much time did nurse have to be nurses -other then helping people
4	Standard of care	About patient's notes - mine were inaccurate.
4	Standard of care	The treatment/care in the operating area, e.g. before surgery whilst waiting to be sedated, as I feel this also should have some attention, as I was looked after in the theatre room by a porter! And was unaware of this until the anaesthetist..
8	Standard of care	Efficiency of doctor in A&E dept.
12	Standard of care	Yes, laxness of O.T. Dept. Complaint went into H.O.D.
12	Standard of care	Yes, time it takes to find problem, worrying for my family also
16	Standard of care	I dare not say. Please take note & get matters improved. The NHS system is nothing to be proud of at this present time. Many persons would agree with my views.
16	Standard of care	Questions about the moral of staff and state of the hospital.
16	Standard of care	Was your dressing changed. No.
4	Success of treatment	Contented with outcome of treatment?
8	Success of treatment	Treatment outcomes - did it make you better?
12	Success of treatment	Did you have to return for care
12	Success of treatment	1) Was the treatment you received (operation etc) a success or not 2) If not, how was this handled by the doctors, staff etc
12	Success of treatment	Any other effects(I developed a post op infection)
12	Success of treatment	Was the treatment successful?
12	Success of treatment	Yes, you should ask about whether your blood test went OK with the people who do them
4	Toilets	Toilets.
12	Transport/ambulance services	Transfers from out hospital to another were not asked. I actually went to [Hospital 1, Trust B] first and was then transferred to [Hospital 2, Trust B] - on the same evening.
16	Transport/ambulance services	No questions about the ambulance staff. (They were excellent)
16	Transport/ambulance services	Yes - Ambulance Crew. Appearance - very smart, attitude - courteous and caring, Treatment - very efficient, Driving - careful, Arrival at A&E - quick attention for smooth handover to staff.
16	Transport/ambulance services	We had immense problems with transport-that was not addressed
16	Type of ward	Yes type of ward C.C.U./cardiac etc.
4	Ventilation/heating	About ventilation! It was very warm, so many people in the same room and windows all shut! Nurses wouldn't open them up, and we were very uncomfortable!
4	Ventilation/heating	Environment, heat and air conditions. Example. Whilst in during hot period. Total lack of air conditioning or suitable cooling system.
8	Ventilation/heating	Temperature in the hospital.
4	Visiting hours	Visiting times not being adhered to
8	Visiting hours	There should be a question re opinion for restricted visiting hours

Pages	Subject	Comment
12	Visiting hours	Visiting hours.
16	Visiting hours	Visitors hours and parking, amount of doctors seen by
4	Waiting for admission / cancellations	How long did you wait for a hospital place?
4	Waiting for admission / cancellations	It would be a good idea to have a form about trying to get admitted to hospital as I had a long ordeal and had to involve my Health community Council several times
4	Waiting for admission / cancellations	More information about waiting time for operations. Especially as I was waiting 6 weeks for a date for a mastectomy. My surgeon would have done it sooner but had to get management approval which is not right. Cancer should not need management approval
4	Waiting for admission / cancellations	Questions regarding booked admissions - i.e. how many times, was it cancelled.
4	Waiting for admission / cancellations	Waiting time for tests and scans seems very long. If these were dealt with faster when out of hospital - waiting times & waiting lists would be cut quite substantially
8	Waiting for admission / cancellations	Have you ever been forced to pay for private treatment due to extreme pain whilst waiting for NHS treatment?
8	Waiting for admission / cancellations	You would not be aware that although satisfied with the care received I waited 18 months for a routine operation after diagnosis. i suffered no pain or inconvenience due to the delay.
8	Waiting for admission / cancellations	Yes I was booked into hospital and when I arrived blood test taken-then discharged by the hospital because no bed had been booked. The nurse on duty was kicking up a fuss because she said in earshot this was the third time this month this had happenned
8	Waiting for admission / cancellations	Did the operation go ahead? If not, why?
8	Waiting for admission / cancellations	Waiting time to see a consultant.
12	Waiting for admission / cancellations	Q. Were you promised an operation then sent home without? A. Yes and I know two other patients who had this treatment.
12	Waiting for admission / cancellations	Having to phone to see if a bed is available is very upsetting and causes a lot of problems when you are turned down and have to go through the proceeding again
12	Waiting for admission / cancellations	About cancellations
12	Waiting for admission / cancellations	Waiting list time?
12	Waiting for admission / cancellations	Was your operation cancelled; were you given enough notice of the cancellation
12	Waiting for admission / cancellations	2.Time you have to wait before you go onto a waiting list
12	Waiting for admission / cancellations	Why left so long, 3 weeks to be transferred to your hospital from another where if I had been moved before I would not have had heart attack the day was admitted to your hospital
16	Waiting for admission / cancellations	Waiting at home for a call to let you know if a bed is available is extremely stressful. You are psyched up for your op and the don't know if you are going into hosp. or

Pages	Subject	Comment
		not.
4	Waiting in hospital	About waiting times whilst you're in hospital
4	Waiting in hospital	In fact you should have asked how long a patient waited from A & E to admission to the ward. Or, how long was the patient left on a trolley
4	Waiting in hospital	Length of time kept waiting, ambulance and length of time spent in A/E.
4	Waiting in hospital	Length of wait to be processed by a doctor length of wait to be admitted to ward bed.
4	Waiting in hospital	The amount of time a person was left waiting in A & E.
4	Waiting in hospital	Time waiting for a bed and to see a doctor in casualty. It took me 5 hours to see a doctor and 12 hours to get a bed in the ward. I was exhausted!
4	Waiting in hospital	Why they did not do the operation at the time I was in hospital. I was in four days on water.
4	Waiting in hospital	Yes people should be asked how long they had to wait for a bed I had to wait 6 hrs on a trolley I admit its not very long in comparison to the length of time other people have had to wait.
8	Waiting in hospital	Question 4 should be completed by ALL as I had a 21/2 hour wait extra, I had to be at hospital at 12.00 for 2pm but finally was treated at 4.30 pm
8	Waiting in hospital	Time of delay between being told you are going for tests actually getting them done!
12	Waiting in hospital	How long did I have to wait to see a doctor... too long.
12	Waiting in hospital	Length of time from assessment to actual examination and start of treatment/admission.
12	Waiting in hospital	Time of arrival to time seeing doctors and privacy
12	Waiting in hospital	Time waiting to be seen in A & E
12	Waiting in hospital	Waiting on the trolleys - in the sight of other patients adds to the panic felt and too crowded, but the medical attention was timely and it is not a complaint, as I have come to no harm at all
12	Waiting in hospital	1.Was there any delay on going to theatre for your operation 2. Was it explained why this delay 3. Did the delay cause any upset/anxiety to you.
16	Waiting in hospital	Was a bed in a ward available? Answer NO!