



National Patient Experience Survey Programme

Cognitive interviews and review to finalise the
questionnaire and invitation letter

February 2017

Table of contents

1. Introduction.....	3
1.1. Background	3
1.2. Developing the survey questionnaire for use in Ireland	3
1.3. Purpose and scope of this document.....	4
2. Purpose and aims of cognitive interviews	5
2.1. Aims of cognitive interviews.....	5
2.2. Information gathered during cognitive interviews.....	5
3. Conducting cognitive interviews	7
3.1. People taking part.....	7
3.2. How cognitive interviews were carried out.....	7
4. Findings.....	9
4.1. Invitation letter: Round 1	9
4.2. Questionnaire: Round 1	9
4.3. Invitation letter: round 2	11
4.4. Questionnaire: round 2	12
4.5. Final review of the questionnaire and invitation letter	13
4.6. Issues relating to analysis and interpretation	15
5. Conclusion and next steps	20
References	21
Appendix 1: information sheet sent to participants	22
Appendix 2: interview protocol for cognitive testing	23
Appendix 3: extract of cognitive interview notes log template	27
Appendix 4: example patient scenarios	28
Appendix 5: draft invitation letter: round 1, round 2 and final.....	30
Appendix 6: NPE Survey instrument including definitions, instructions and routing – round 1, round 2 and final	34

1. Introduction

1.1. Background

The National Patient Experience (NPE) Survey is a new national survey asking patients about their recent experiences in hospital. Its purpose is to learn from this feedback to improve the planning and delivery of healthcare.

The NPE Survey Programme is being carried out by three organisations working as partners: the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. HIQA is the lead partner with responsibility for delivering the survey and reporting on the results.

The NPE Survey questionnaire will be sent to all people aged 18 or over with a postal address in the Republic of Ireland, who have spent one night or more in a public acute hospital, and were discharged in the month of May 2017. Results will be published at the end of 2017¹.

1.2. Developing the survey questionnaire for use in Ireland

The starting point for the NPE Survey questionnaire was a library of 189 questions⁽¹⁾ on hospital inpatient experience from Picker Institute Europe². This library was reduced to a set of 100 items, 60 of these 'high priority', through the following three processes:

- first, HIQA conducted eight focus groups, involving 62 individuals, in May and June 2016. Six of the focus groups were conducted with patients in one hospital drawn from each of Ireland's hospital groups. Two focus groups were conducted with data users in Dublin and Cork. Results of the focus group interviews were published in August 2016⁽²⁾.
- second, HIQA carried out a two-round Delphi study³. A panel consisting of 60 patients and 'experts' from across the healthcare service was appointed. In the first round, the panel reviewed all 189 items 'as is', while in the second round, focus group feedback was included. This process allowed the 'top 100' questions to be identified. The top 60-rated questions among these were considered a priority for inclusion in the final version of the questionnaire. The top 100 questions were also mapped against HIQA's National Standards for Safer Better Healthcare (NSSBH). The results of the Delphi study, including

¹ Further information is at www.patientexperience.ie.

² Picker Institute Europe, established in 1986, is an international charity working across health and social care dedicated to developing a patient-centred approach to healthcare (www.picker.org).

³ A Delphi study is a method that is used to reach agreement on which items on a list are most important, or of the highest priority.

how results were integrated with focus group feedback and mapped to NSSBH, were published in 2016⁽³⁾.

- third, to ensure that the questions selected for inclusion provide the greatest value in terms of feedback for the healthcare service, HIQA consulted Picker Institute Europe for advice on the set of 60 items proposed for the survey questionnaire (from the first two steps above). As a result of this consultation, 49 of the 'top 60' items were recommended for retention, and 11 recommended for deletion. Items were dropped due to weak psychometric (measurement) properties and/or overlaps with other items in the set. Eleven items (six from the 'reserve' 40 and five new or unranked) were recommended for inclusion for three reasons: they were required for routing (directing the respondent to the next question that applied to them), they were formed from combining existing items, or they asked for essential demographic information that was not included in the top 100 items. The outcomes of the consultation with Picker Institute Europe have also been published⁽⁴⁾.

1.3. Purpose and scope of this document

This short report describes the fourth stage of the development of the NPE Survey questionnaire, cognitive interviewing, and the final changes made to the questionnaire following review by the NPE Survey Programme governance groups and managed service⁴. The report is organised into five sections (including this one):

- section 2 describes the purpose and aims of cognitive interviews for the NPE Survey questionnaire and invitation letter
- section 3 explains how the cognitive interviews were carried out
- section 4 describes the results of the cognitive interviews, and the changes made to the questionnaire and invitation letter in response to the information gathered in the interviews. It also summarises the changes made to the questionnaire following final review by the governance groups and managed service.
- section 5 explains how the cognitive interviews and final review, along with the other stages in the development of the questionnaire, result in a questionnaire and invitation letter that are suited to the Irish context. It also notes issues raised during the interviews and the final review.

⁴ The NPE Survey Programme is overseen by a Steering Group, Delivery Group, and Advisory Group with representatives from the three partner organisations as well as patient representatives. The Managed Service administers the survey on behalf of HIQA.

2. Purpose and aims of cognitive interviews

The purpose of cognitive interviewing, or cognitive testing, is to identify and correct problems with the survey tool (questionnaire), and to contribute to the analysis and interpretation of the survey data^(5, 6).

Since the 1980s, cognitive interviewing has become more widely used in survey development and design⁽⁷⁾. Despite this increasingly common practice, there is no widely agreed definition as to what exactly it is. Beatty and Willis^(7, p. 288) suggest that cognitive testing involves "...administering draft survey questions while collecting additional verbal information about the survey responses, which is used to evaluate the quality of the response or to help determine whether the question is generating the information that its author intends."

2.1. Aims of cognitive interviews

The main aim of the cognitive interviews described here is to assess the clarity and appropriateness of the proposed NPE Survey questionnaire (including cover page, instructions and definitions) and initial invitation letter. A second aim of this exercise is to document any issues in interpreting the survey questions and response options in order to guide interpretation of the results.

Cognitive interviewing is often followed by piloting⁵ of the survey tool. However, piloting was not planned, since the questions are already internationally validated. The objective was instead to evaluate the extent to which the 'packaging' of the survey tool with its layout, instructions and definitions, along with the invitation letter, worked as a whole.

2.2. Information gathered during cognitive interviews

Cognitive interviews for the NPE Survey gathered detailed, structured feedback from patient group representatives on:

- the clarity and appropriateness of the wording of the invitation letter
- the clarity and appropriateness of the wording of the cover page
- the clarity of wording of questions and response options
- the logical flow and routing logic
- the adequacy of instructions and definitions
- the overall layout and style, including font size.

⁵ Piloting in this sense involves administering the questionnaire to a small number of people before the main survey to test the questionnaire (as regards wording, timing and so on).

Cognitive interviewing did not focus on changes to question wording or response options because the questions are already tested and validated⁽¹⁾. Instead, its focus was on (1) identifying any difficulties in layout, routing and flow, (2) identifying and understanding difficulties respondents had in answering, and (3) gathering contextual information that may influence how respondents interpret and consequently answer questions.

In order to gather information on how response rates could be maximised for the NPE Survey, the cognitive interviews asked about two further aspects of both the questionnaire and the invitation letter: (4) whether these materials are sufficiently engaging to motivate people to respond, and (5) whether they are sufficiently reassuring to allow respondents to trust that the information that they are providing will be treated ethically and securely.

Broadly speaking, cognitive interviews gather information using two methods: think-aloud (where participants verbalise their thought processes) and probing (focused, structured questions where participants explain their responses and/or offer their views)⁽⁷⁾.

For this study, a probing method was used, where respondents are asked a set list of questions about the invitation letter and questionnaire. The questions are aligned to the cognitive model⁽⁸⁾ of question response (comprehension, retrieval, judgement, response), with the addition of questions that ask for participants' views on whether or not the materials provide motivation to respond, and reassurance about data confidentiality and security.

3. Conducting cognitive interviews

3.1. People taking part

Table 1 shows details of each of the cognitive interview sessions. Participants were recruited through the patient representative groups of four Dublin hospitals and one Galway hospital. Interviews were conducted in two rounds with a total of 10 participants. Following round 1, suggested changes and improvements were made to the invitation letter and NPE Survey questionnaire. The revised versions were then used in round 2.

Table 1: Details of cognitive interview participants and sessions

Date	Length	Sex	Location	Perspective	Round
12 Jan. 17	75 min	Female	Dublin	Relative of patient	1
13 Jan. 17	94 min	Female	Dublin	Patient and relative of patient	1
20 Jan. 17	93 min	Female	Dublin	Patient and nurse	1
20 Jan. 17	88 min	Male and Female	Dublin	Patient (male) and relative of patient (female)	1
23 Jan. 17	39 min	Female	Galway	Patient and relative of patient	2
24 Jan. 17	85 min	Male	Galway	Patient	2
26 Jan. 17	65 min	Male	Dublin	Patient	2
26 Jan. 17	47 min	Female	Dublin	Patient	2
26 Jan. 17	64 min	Male	Dublin	Patient	2

- Round 1: on average, cognitive interviews lasted 87.5 minutes and took place between 12-20 January 2017. One man and four women took part.
- Round 2: on average, cognitive interviews lasted 65.3 minutes and took place between 23-26 January, 2017. Three men and two women took part.

3.2. How cognitive interviews were carried out

Before meeting with the researchers from HIQA, participants were sent information about the purpose of the cognitive interviews (Appendix 1). Two researchers in the NPE Survey Team met each participant individually (except for one round 1 interview, in which both a patient and his relative took part).

One researcher went through the structured interview protocol (Appendix 2) while the second researcher took structured notes in a log file (Appendix 3). To assist with the process, a fictitious (pretend) patient scenario (Appendix 4) was given to the participant and they were advised to go through the questionnaire using the

information provided in the scenario. The scenarios were developed to try to avoid having the participant recall possible upsetting events during the cognitive interview. In practice, however, participants tended not to use the scenarios. They preferred to review the materials based on their own experiences and/or critical perspectives.

Both the draft invitation letter (Appendix 5) and questionnaire (Appendix 6) were reviewed during each interview. The structured interview protocol (Appendix 1) provided some assurance that the sessions were conducted in a standardised way.

Before starting the interview, verbal consent was obtained from participants. At the end of the interview, participants were asked if they wanted to receive a copy of the report on the cognitive interviews. Identifying information (name, email, phone number, postal address) was used solely for the purposes of contacting participants and sending on the report on the sessions. The log of interviews did not contain any identifying information.

Following round 2, further revisions were made on the basis of comments recorded in the log file.

As soon as possible after each interview, the researchers compared and reconciled handwritten notes and the log file. These were then subjected to a broad thematic analysis to identify (1) issues with wording of any of the materials other than the questions and their response options, (2) suggestions for improvements to any of the materials other than the questions and their response options, (3) comments on the question wording, (4) comments on response options, (5) comments on what was not covered in the questions, and (6) descriptions of hospital experiences, either based on actual events, or what participants know about specific hospital practices and processes.

Information and observations under (1) and (2), and in a couple of instances, (3), were used to make changes to the questionnaire and invitation letter, while (3), (4), (5) and to a lesser extent, (6) were reviewed to better understand some of the issues that might arise during interpretation of the results.

Following the cognitive interviews, the questionnaire and invitation letter were reviewed by the NPE Survey Programme governance groups and the managed service. Additional changes suggested by these groups are described in Section 4.5.

4. Findings

This section describes the results of the cognitive interviews and the final review of the questionnaire and invitation letter by the NPE Survey Programme governance groups and managed service. It summarises:

- changes made to the invitation letter following the first four cognitive interviews (round 1)
- changes made to the questionnaire following the first four cognitive interviews (round 1)
- changes made to the invitation letter following the first last five cognitive interviews (round 2)
- changes made to the invitation letter following the last five cognitive interviews (round 2)
- changes following the final review by the governance groups and managed service.
- issues relevant to the analysis and the interpretation of results.

Please refer to Appendix 5 and Appendix 6 for more information about the changes made to the letter and the questionnaire following round 1 and round 2 of the cognitive interviews and the final review.

4.1. Invitation letter: Round 1

Overall, participants felt that the length, layout and font size of the letter were fine. Participants were either neutral to, or in favour of, the signatory. All participants had suggestions for improvement. These can be summarised as follows:

- avoiding 'policy speak' and replacing this with more personal phrasing
- making a direct appeal for help, and accompanying this with the message that responding to the questionnaire will make a difference
- providing stronger reassurance that the data is anonymous, and will not affect current or future healthcare
- better highlighting the website, Freephone number and email address.

(Appendix 5 shows the invitation letter used in round 1, round 2, and the final proposed letter.)

4.2. Questionnaire: Round 1

The scope of possible changes is limited by the fact that item selection had already taken place from an internationally validated library of questions. For this reason, changes in the wording of the international questions and their response options, unless consistently and seriously problematic, were not considered. It was not

possible to consider additions, since the questionnaire was already set to a 60-question limit.

All round 1 participants made positive comments about the questionnaire, particularly with respect to the layout. Overall they found the questionnaire and its instructions clear, and had no difficulties with its length. They were also generally satisfied with the content. Specific issues with the content are described in Section 4.5.

The changes made to the questionnaire as a result of the round 1 interviews are shown in detail in Appendix 6. These are:

Cover page:

- including the statement 'Please help us improve our healthcare system' at the top of the cover page in order to be more personal and appeal directly to the participant
- making the introductory text under 'What is this survey about?' less "policy speak" and more appealing to personal experience. This text should also emphasise that responding to the questionnaire will make a difference
- removing specific instructions on routing (as these provide unnecessary and potentially off-putting detail)
- making contact details (website, email, freephone) more prominent.
- adding the following sentence at the end for reassurance: 'Your feedback will not affect your future care in any way'.

Changes to the instructions, definitions and questions (see Appendix 6):

- instructions prior to Q1 were altered to have a larger font so that they are more likely to catch the participant's eye. The instructions highlight that the survey concerns the patient's most recent stay in the hospital named in the letter. This is relevant for respondents who have had multiple admissions/discharges in the survey month
- additional part to the definition of a ward prior to Q8 (for patients being admitted through the Emergency Department). The existing definition reads: 'A **ward** is a room or area in the hospital where patients receive care following admission'. We added: 'This is where you received your care **after** you were moved out of A&E' to make this definition clearer for respondents coming into hospital through the Emergency Department
- definition of 'tests' prior to Q30 was edited to include a more complete and familiar list of examples, as follows: '**tests** do not include blood or urine tests.'

They are used to assess your needs or identify your condition. Examples of **tests** include: ECG, x-ray, CT scan, MRI scan, ultrasound'

- Definition of 'operations and procedures' prior to Q54 was edited to include a more complete and familiar list (including a change from 'appendectomy' to 'removing an appendix') as follows: '**Operations** and **procedures** do not include tests and treatments. Examples of **operations** and **procedures** include: triple bypass, repairing a broken bone with surgery, removing an appendix, hysterectomy, colonoscopy, lumbar puncture/spinal tap'
- the reminder note prior to Q54 was changed from '**Reminder:** all the questions should be answered...' to '**Please keep in mind** that all questions should be answered...' to make the tone less formal and more friendly
- Q57, which asks whether respondents currently hold a medical card and/or private health insurance, was the only 'tick all that apply' question in round 1 ('Do you currently have a medical card and/or private health insurance? I have a medical card, I have private health insurance, I do not have a medical card **or** private health insurance'). For round 2, its format was simplified to a two-part question, each part with a yes/no response: 'Do you currently have a medical card?' 'Do you currently have private health insurance?'
- instructions prior to Q58-Q60 were altered to thank respondents for taking part, provide stronger encouragement to make comments, emphasise anonymity, and advise respondents not to provide their own name or the name of hospital staff.

4.3. Invitation letter: round 2

During round 2, all participants made unprompted positive comments about one or more changes to the letter, which indicates that at least some of the round 1 changes represent improvements. The most common kind of positive feedback related to the more personal language used, with respondents liking the text 'Please help us improve our healthcare system' and 'Your views will make a difference'. Suggestions for improvements from round 2 fell under three areas:

- the opt-out process is not clear enough and should be separated from the processes for responding
- the detail on reporting plans is not needed
- minor editorial fixes are needed to improve clarity.

4.4. Questionnaire: round 2

The changes made to the questionnaire following suggestions and observations of participants in the round 2 interviews are shown in detail in Appendix 6. These are:

Cover page:

- the font size of the statement 'Please help us improve our healthcare system' at the top of the cover page was increased to highlight the direct appeal to engage with the survey more
- the reference to 'acute' was removed since participants in both rounds 1 and 2 wondered if its meaning was clear and/or whether it was necessary
- a new section headed 'Can I complete the questionnaire online?' was added to promote online survey uptake
- the text under 'Do I need to fill this out myself?' was shortened and clarified, since some of the respondents in both rounds 1 and 2 found these a little unclear
- to provide further reassurance of confidentiality and based on round 2 suggestions, the sentence 'Please do not write your name or address anywhere on the questionnaire' was put in bold
- to better signal that respondents would be encouraged for open-ended feedback, a sentence was added under 'Completing the questionnaire': 'There is space at the end of the questionnaire for your written comments'. Round 2 feedback suggested that this might encourage respondents to reflect on comments that they may wish to make while completing the closed questions 1-57.

Changes to instructions, definitions, and questions (see Appendix 6 for details):

- response option 2 to Q1 (Was your most recent hospital stay planned in advance or an emergency?) was changed from 'Waiting list or planned in advance' to 'Planned in advance or waiting list' to better cue in the respondent to the response option
- the reference to 'surgical' was removed from the examples in Q2 ('also known as the Emergency Department, Casualty or Medical or Surgical Assessment Unit') so as to eliminate any confusion between planned surgical procedures and emergency admissions
- the definition of ward for patients coming in via the Emergency Department had additional text ('following admission', 'you were moved out of A&E') put in bold as follows: 'A **ward** is a room or area in the hospital where patients receive care **following admission**. This is where you received your care **after you were moved out of A&E**'

- the sections on 'Doctors' and 'Nurses', each containing two questions, were put into the section 'Your Care and Treatment' (without their separate headings). This was done because some respondents asked why there were so few questions on doctors and nurses, while others asked why other hospital staff, such as nursing assistants and physiotherapists, were not included
- further minor refinements were made to the definitions of tests, and to operations and procedures
- a definition for treatments was put into a box in a manner consistent with those for tests, and operations and procedures, as some respondents asked why there was no definition for treatments. Related to this, the examples of treatments were removed from the question stems of Q34 and Q35.
- Q43 asks: 'Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home?' Here, 'doctors and nurses' was changed to 'healthcare staff' to better reflect the national context (where staff other than doctors and nurses can be involved in the discharge process)
- an explanatory note was added to Q56 (ethnicity) and Q57 (medical card and private health insurance status) stating that this information is gathered 'to know if the people who responded to the survey represent all sections of our society'
- the format of Q57 (medical card and private health insurance) was merged from two yes/no questions to a single question as follows: 'Do you currently have: A medical card/Private health insurance/**Both** medical card and private health insurance/**Neither** private medical card nor private health insurance'
- minor refinements were made to the instructions preceding the three written-response questions (Q58-Q60).

4.5. Final review of the questionnaire and invitation letter

The questionnaire and invitation letter were reviewed by the NPE Survey Programme governance groups (the Advisory Group, Delivery Group, and Steering Group) and the managed service during February and early March.

This is an important final step, since it ensures that the three partner organisations have had a chance to review and agree on the content of the survey tool, as well as ensuring that these materials reflect the administration processes planned by the managed service.

4.5.1. Changes to the letter

The following changes were made to the invitation letter:

- the very top of the letter was changed from 'National Patient Experience Survey: Help us to improve hospital care' to 'Please help us make hospital care better'. This relates to the first point below under 4.5.2, 'Changes to the questionnaire'
- the first line explicitly states 'a national survey'
- in the third paragraph, 'no-one will know if you took part' was deleted. For the purposes of administering the survey only, response and non-response need to be tracked centrally. Responses, however, remain anonymous at all times.

4.5.2. Changes to the questionnaire

- While the advisory and Steering groups agreed that a direct appeal for help was needed on the cover page of the questionnaire, there were mixed views about the wording proposed in the cognitive interviews ('Please help us to improve our healthcare system'). Following discussion, the wording was changed to 'Please help us make hospital care better.'
- Respondents' written comments may appear in published reports of the results. Therefore, the sentence 'Your answers will be treated in confidence' was changed to 'Your answers will remain anonymous.'
- To minimise the risk of the NPE Survey questionnaire being used to make specific complaints, the Steering Group recommended adding the following note to the cover page, under 'What is this survey about?': 'Please use this survey to provide general feedback about your hospital experience. If you would like to make a comment, compliment or complaint and receive a response, please email the HSE at yoursay@hse.ie, phone 1850 1890 424 555, or go to www.healthcomplaints.ie.'
- The managed service recommended not to use email for opting out because the opt-out process can only be managed effectively if the person's survey code is known, and this may not be the case with email. The instructions about completing the questionnaire and opting out on the cover page were amended to reflect this recommendation.
- The managed service also recommended promoting online survey participation more, since this is a faster and cheaper way to manage survey responses. The instructions under 'Can I do the questionnaire online?' were changed to 'Yes, please complete the survey online if possible. This can be done on a computer, smartphone or tablet at **www.patientexperience.ie**.'

However, if you prefer, you can complete this paper version of the survey and use the **Freepost** envelope to return it.'

- The managed service recommended that the cover page should include the Freephone hours (Monday-Friday, 9am-5pm).
- The Steering Group recommended that references to Accident and Emergency/A&E should be changed to the more correct term, Emergency Department.
- The Delivery Group noted that Q55, which asks for year of birth of the respondent, should also include month of birth, to be able to calculate age in a more accurate manner.
- Following discussion with the Delivery Group and Steering Group, it was agreed to include one question from the Picker library that had not been prioritised among the top 60 during the Delphi rating process. This was an overall rating of patient experience, on a 0-10 scale. This question was included due to high endorsement by all six patient focus groups and also because there was no other question on overall patient experience in the questionnaire. Discussion with the managed service confirmed that the inclusion of this overall question would be useful in analysis, for example in helping to identify national priorities. This question is recommended by the Picker Institute Europe⁽⁹⁾, which notes that another advantage of this question is that its wording is sufficiently general for inclusion in surveys of other aspects of hospital care, for example maternity services.
- The instructions before the last three questions, which asked for written comment, were amended to be more closely in line with best practice for fully informing the respondent about how results would be used. The amended version is as follows: 'Thank you very much for taking part in this survey. Please feel free to tell us about your hospital stay in your own words in the boxes below. You can use the back page of the questionnaire if you need more space. Comments will be entered into a secure database after removing any information that could identify you. This anonymised feedback will be looked at by HIQA, the HSE and the Department of Health to try to understand and improve patients' experience in hospital. We will give examples of feedback in the final survey reports to provide a fuller understanding of patients' experiences.'
- Use of UPPERCASE was removed throughout the questionnaire.

4.6. Issues relating to analysis and interpretation

Broadly speaking, the issues identified during the cognitive interviews can be classified as: (1) relevant to interpreting the responses and (2) gaps in content covered. While we did not ask the cognitive interview participants about gaps in the

content covered, this was a theme common to all interviews. These are summarised below.

In addition, during their final review, the Steering Group asked HIQA to explore the feasibility of including a question on reason for admission to hospital. The outcomes of this are also discussed below.

It is recommended that points described in this section are taken into account when interpreting findings, reporting on the limitations of the survey, and planning future developments of the NPE Survey.

With respect to issues relevant to **interpretation**:

Demographic questions:

- in both Rounds 1 and 2, participants made comments on Q56 (respondent's ethnicity) and Q57 (medical card and private health insurance status). There was a range of views – while most participants felt that these questions were fine, and expected them in a survey like this, some wondered why the questions were being asked. This confirms that comparisons of the rate of missing responses by age, gender and region for these questions should be built into the analysis
- three participants asked 'what was the point' of Q56 and Q57. This contrasts with the responses to the questions on sex and year of birth, which did not give rise to any comments or queries
- three participants commented that some respondents, particularly non-Whites, may find the question sensitive. It should be noted that Q56 is based directly on the Census 2016 question from the CSO
- fewer participants raised concerns about the sensitivity of the question on medical card/private health insurance. However, one participant wondered whether some respondents might be reluctant to respond in case this had an impact on their medical card entitlement
- in response to queries raised by participants about the reason for including Q56 and Q57, we added a note to explain that we asked the questions to know 'if the people who responded to the survey represent all sections of our society'. The reports on the survey need to include information on whether some groups in the population are under- or over-represented.

Response options:

- the observations below indicate that the analysis should include a consideration of collapsing (combining) some of the 'yes' response options when reporting the results
- two of the participants focused on the variation in the wording of response options and/or perceived inadequacies in them, and offered differing views. One participant felt that having the 'yes' response split into two parts ('yes, definitely'/'yes, to some extent') was unnecessary and a simpler 'yes/no' format would be better. The other respondent commented on the unevenness of the response categories, and felt that the 'middle' category was closer to a 'no' than a 'yes'. For example, given 'yes, always/yes, sometimes/no', he would have preferred 'yes, always/yes, mostly/yes, sometimes/no'
- some participants noticed that the response options varied, for example 'yes, definitely/yes, to some extent', 'yes, completely/yes, to some extent', 'yes, always/yes, sometimes', and wondered why this was the case
- some participants also noted inconsistencies in response options used across questions that they perceived to be similar. For example, Q33 does not provide a response for people who do not want to know results of tests while Q34 and Q35 do provide a response option for people who do not want an explanation about treatments.

Theme of communication:

- the observations regarding communication suggest that this is a theme where qualitative analysis of the written responses could be particularly useful, and where comparisons by age and sex on relevant numeric questions should be included in the analyses
- the area of communication between staff and patients was acknowledged by a majority of participants as complex for two main reasons. First, there may be a cultural or local aspect whereby patients may be reluctant to ask questions of staff. Second, the distinction between fluency in the English language and the ability of staff to communicate medical information in plain English may be important. The numeric (tick-box) questions cannot 'get at' these issues directly
- furthermore, the cognitive interview participants felt that there may be age-related variations in responses to questions about communication, asking questions and participating in decisions and it will be important to include age-based comparisons of these areas in the analyses.

Specific questions:

- a number of specific questions were perceived to be a little vague, unclear, subjective or 'off-target'. The observations of participants summarised below should be referred to during analysis, and where appropriate, built into commentary in reporting on the results. In each case, these observations were made by between one and three participants
- Q25 ('How much information about your condition or treatment was given to you? Not enough/the right amount/too much') was perceived to be subjective and difficult to quantify, and likely to vary with individual expectations
- Q24 and Q40, which ask about level of involvement in decisions relating to treatment (Q24) and discharge (Q40) were felt to be a bit 'off target' since, in many cases, there is no patient involvement in decisions, or at least the assumption that there is no involvement
- It was felt that the difference between two of the response options for Q33 ('Did a doctor or nurse explain the results of the tests in a way that you could understand?' – 'no' and 'I was never told the results of tests') were felt to be too subtle. It was felt that not everyone would pick up on this
- the wording and examples for Q35 ('Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand?') were felt to be contradictory given that a *protective* intervention, a dressing, is an example of a treatment, while the question mentions 'risks'. Comments from some participants suggested that very few respondents would answer 'yes', suggesting that this item might not provide much useful information
- some participants felt that three of the questions on communication about operations and procedures (Q36, explaining risks and benefits; Q37, answering questions; and Q38, explaining how patient could expect to feel) overlap; one or more may be redundant
- similarly, there may be redundancy in Q41 and Q42. Q41 asks if the respondent was given enough notice of discharge and Q42 asks if the family was given enough notice.

During the cognitive interviews, all participants identified one or more **gaps** in the content covered. These arose spontaneously in discussion and are summarised below. It is recommended that note is taken of these in reporting limitations with survey coverage and also in planning for any future developments of the NPE Survey Programme. One or more participants noted that:

- the questionnaire does not ask about specific **hospital staff** other than nurses or doctors. Examples mentioned by the cognitive interview participants include physiotherapists, speech and language therapists and nursing assistants
- **emotional support** while receiving bad news, and privacy for receiving this news, is not covered
- since the questionnaire includes only one question about **pain**, this may pose challenges in using the results for making improvements to pain management
- relating to **medication**, changes in medication while in hospital, and self-medication (for pain, sleep) are not asked about
- the questionnaire does not ask whether this is the **first admission** of the person to the hospital in question. One participant commented that familiarity with hospital procedures may affect how patients perceive their care
- some respondents commented that responses to questions on **receiving help**, for example, with meals or getting to the toilet, may be due to a variety of reasons, such as unwillingness to ask for help, staff shortages, inefficiencies, etc., and the questions do not directly measure these reasons
- the section on **leaving hospital** does not ask respondents for the reason for a delay in discharge, if one was experienced.

The Steering Group felt that a question on the **reason for admission** to hospital should be included because it provides potentially useful information. For example, it could allow for comparisons of hospital experience between people admitted for planned and unplanned procedures, treatment of a long-term condition, and so on. However, a question on the reason for admission did not feature in the 100 questions that went through the focus group- and Delphi processes.

None of the national patient experience surveys from England⁶, Scotland⁷, Canada⁸ or the US⁹ include a question on reason for admission, and in England and Scotland, this information is extracted directly from hospital information systems.

Patient representatives were asked for their views on the inclusion of a question on reason for admission. They were generally in favour of including it, and felt that it would not be overly sensitive, provided that it was asked at a fairly general level.

⁶ See <http://nhssurveys.org/surveys/833> and (<http://nhssurveys.org/surveys/935>).

⁷ See <http://www.gov.scot/Topics/Statistics/Browse/Health/InpatientSurvey/Inpatient2016> and <http://www.adls.ac.uk/nhs-scotland/general-acute-inpatient-day-case-smr01/?detail>.

⁸ See <https://www.cihi.ca/en/health-system-performance/quality-of-care-and-outcomes/patient-experience>.

⁹ See <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS.html>.

Since no existing question was available from the patient experience surveys in England, Scotland, Canada and the US, piloting of a new question would be required, and the project timeline did not provide for this. It is recommended that this information is collected in the next round of the NPE Survey (assuming the programme continues beyond 2017).

5. Conclusion and next steps

The NPE Survey questionnaire (Appendix 6) has now gone through a four-step process to ensure that it includes questions that are important to patients, data users, and other stakeholders in the Irish context.

The aims of the cognitive interviews were to assess the clarity and appropriateness of the NPE Survey questionnaire and invitation letter, seek feedback on ways to encourage people to respond and to assure them of anonymity, and identify issues in interpretation to guide analysis and reporting. The cognitive interviews were followed by a final review by the NPE Survey governance groups and managed service.

The changes made to both the questionnaire (Appendix 6) and invitation letter (Appendix 5) following the cognitive interviews and final review provide assurance that, within the constraints of the survey programme (i.e. the fact that survey questions are already internationally validated, the questionnaire cannot be any longer than it is, and the time available to finalise the questionnaire), these aims have been achieved.

Finally, it will be important to take account of the issues described in Section 4.6 in the analysis, interpretation and reporting of the results, as well as in planning for future rounds of the NPE Survey Programme.

References

1. Jenkinson, C., Coulter, A., Bruster, S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. 2002. *International Journal for Quality in Health Care*. 2002, 14 (5) 353-358; DOI: 10.1093/intqhc/14.5.353. Available online from: <http://intqhc.oxfordjournals.org/content/14/5/353>. Accessed on 5 November 2016
2. Health Information and Quality Authority. Statement of Outcomes: Patient-led focus groups for the National Patient Experience Survey. 2016. Available from: <http://www.patientexperience.ie>.
3. Hanafin S. Report on the Delphi Study to Identify Key Questions for Inclusion in the National Patient Experience Questionnaire. 2016. Research Matters Ltd. Available from: <http://www.patientexperience.ie>.
4. Health Information and Quality Authority. National Patient Experience Survey Programme: Consultation meeting with the Picker Institute Europe on finalising the NPE Survey questionnaire. 2017. Available from: <http://www.patientexperience.ie>.
5. Miller, K., Chepp, V., Wilson, S., Padilla, J.L. (Eds.). Cognitive interviewing methodology (Wiley Series in Survey Methodology). 2014. Hoboken, NJ: John Wiley & Sons.
6. Statistics Division, Economic and Social Commission for Asia Pacific Region. Guidelines for cognitive and pilot testing of questions for use in surveys: ESCAP project on improving disability measurement and statistics in the Asia Pacific region. 2010. Available online from: <http://www.unescap.org/resources/guidelines-cognitive-and-pilot-testing-questions-use-surveys>. Accessed on 31 January 2017.
7. Beatty, P.C., Willis, G.B.. Research synthesis: The practice of cognitive interviewing. 2007. *Public Opinion Quarterly*, 71 (2), 287-311.
8. Willis, G.B. Cognitive interviewing: A tool for improving questionnaire design. 2005. London: SAGE Publications.
9. Graham, C., MacCormick, S. (2012). Overarching questions for patient surveys: development report for the Care Quality Commission (CQC). London: Picker Institute Europe.

Appendix 1: information sheet sent to participants

Note meeting dates and times depended on the person or group contacted.

National Patient Experience Survey Programme Cognitive testing of survey pack – Information for participants

The purpose of **cognitive testing** is to see if the survey pack for the National Patient Experience Survey is clear and contains all of the relevant information, and that the questions, instructions and layout of the questionnaire make sense.

The survey pack contains:

- An invitation letter
- An information brochure
- A copy of the National Patient Experience Survey questionnaire.

We want a final survey pack that includes clear guidelines on how to complete the questionnaire. We want the questionnaire to be easy to understand and well-designed. Your participation in the cognitive testing will help us to achieve this.

The cognitive testing will involve:

- Introducing ourselves (**Jude Cosgrove** and **Tess Huss** from **HIQA**) and answering any questions that you may have
- Reading through the letter and providing feedback or suggestions for improvement, if you have any
- Filling in the questionnaire, pointing out to us any questions or instructions that are not clear to you as you go along.

The session will last at most **an hour and a half**. One of us will make notes of your views and comments, while the other may ask you questions or ask you for suggestions for improvements.

Your feedback is extremely important. It will be gathered anonymously. We will not identify you by name or any other personal details. We will combine the information from all of the people who took part in the cognitive testing and use this to finalise the wording and layout of the survey materials.

When we report on the results, we will describe how we used the cognitive testing to finalise the survey materials.

The **90-minute** cognitive testing sessions will take place in the **HIQA offices** in George's Court, George's Lane, Smithfield, **Dublin 7**, on **Fri Jan 13** and **Fri Jan 20**, at **9:30am, 11:30am, 1:30pm** and **3:30pm**.

What do I do next?

If you would like to take part, please email or phone **Jude** at icosgrove@hiqa.ie or **01 8286715** and let us know which date(s) and time(s) might suit. Please email or phone Jude if you have any questions.

Thank you very much for taking the time to read this information. We hope that you are able to take part.

Appendix 2: interview protocol for cognitive testing

We'll go through the letter and the questionnaire section by section, and ask you to read each section. You can use the example patient information to fill them out. Then we'll ask you for feedback.

I'll guide you through the letter and the questionnaire, and Tess/Jude will take notes.
Is that OK? Do you have any questions?

Date: _____ ED/Planned: _____ Time1: HH:MM _____

A – Letter. *Information/instructions:* This is the cover letter that is sent with the questionnaire. Please read it, and then we'll ask for your feedback.

1. Do you think it does a good job in getting across what the survey is about and why it is important to take part?
2. Are there any words or phrases that are difficult to read or understand?
3. Is it too long, too short...?
4. Would you prefer if a different person or people signed the letter?
5. Can you think of any ways to improve the letter?

B – Cover page. *Information/instructions:* Some of the information on the cover page repeats the information on the cover letter. We did this because some people might lose the letter before they start doing the questionnaire. Please read it, and then we'll ask for your feedback.

1. Do you think it does a good job in getting across what the survey is about and why it is important to take part?
2. Are there any words or phrases that are difficult to read or understand?
3. Is it too long, too short...?
4. Would you have any concerns about how your information will be used after reading the instructions?
5. Can you think of any ways to improve the cover page?

C – Page 2 – Admission. *Information/instructions:* Please read the first two questions on page 2 and answer them using the example patient information.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?
3. Both of these questions include instructions for you to skip to another question. Did you have any trouble following these instructions?

D – Page 2 – A&E Department. *Information/instructions:* Please read the rest of the questions on page 2 and answer them using the example patient information.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?
3. How did you find Q7? Are the instructions after Q7 clear?

E – Page 3 – Ward and Q8. *Information/instructions:* Take a look at the box at the top of page 3 and also at Q8 and answer it using the example patient information.

1. Does information in the box make sense to you or could we make it clearer?
2. How did you find answering Q8? Were you put off by the amount of possible boxes to choose from or the instructions?

F – Page 3-4 – Hospital and Ward. *Information/instructions:* Please read the rest of the questions on page 3 and the first question on page 4 and answer them.

1. Does the information in the box make sense to you or could we make it clearer?
2. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
3. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?

G – Page 4 – Hospital Food. *Information/instructions:* Please read the questions on page 4 in the Hospital Food section and answer them.

1. Did you find the wording of the questions clear?
2. Were there any words or phrases that you found unclear?
3. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?
4. How did you find the instructions for Q15 and Q17?

H – Page 4 – Doctors. *Information/instructions:* Please read the two questions on page 4 in the Doctors section and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?

I – Page 5 – Nurses. *Information/instructions:* Please read the two questions on page 5 in the Nurses section and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?

J – Page 5-6 – Your Care and Treatment and Pain. *Information/instructions:* Please read the questions on pages 5 and 6 in the Care and Treatment and Pain sections and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?

K – Page 6 – Tests. *Information/instructions:* Take a look at the box under Tests and answer Q33.

1. Does information in the box make sense to you or could we make it clearer?
2. How did you find answering Q33? Were you put off by the amount of possible boxes to choose from?

L – Page 6-7 – Treatments. *Information/instructions:* Take a look at the two questions under Treatments and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble in choosing which box to tick for either of the questions? Can you tell us more about this?
3. How did you find the instructions for Q34?

M – Page 7 – Operations and Procedures. *Information/instructions:* Take a look at the box and questions in the Operations and Procedures section and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?
3. How did you find the instructions for Q36?

N – Page 7-9 – Leaving Hospital and Overall . *Information/instructions:* Take a look at the questions in the Leaving Hospital and Overall sections and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?
3. How did you find the instructions for Q45?

O – Page 9-10 – About You. *Information/instructions:* Take a look at the questions in the About You section and answer them.

1. Did you find the wording of the questions clear? Were there any words or phrases that you found unclear?
2. Does information in the box under Q53 make sense to you or could we make it clearer?
3. Did you have any trouble choosing a response to any of the questions? Can you tell us more about this?
4. Would you have any concerns about providing the information asked in this section? Can you tell us more about this?
5. What did you think of Q57?

P – Other Comments. *Information/instructions:* Take a look at the instructions and questions in the Other Comments. If you want, you can write some comments based on the example patient information.

1. Do you think the instructions are clear? Could they be improved?
2. Would you feel motivated to write in comments? Why is this?
3. Would you have any concerns about providing information in this section? Can you tell us more about this?
4. Can you think of any ways to improve this section?

Q – Overall Impressions. *Information/instructions:* Thinking now about the questionnaire as a whole, do you have any other thoughts?

1. For example, on the way questions are laid out, instructions, the size of the text, the length of the questionnaire – any feedback you have is useful.
2. There is additional information and instructions in boxes in the questionnaire. What did you think of these? For example are they visible enough, is the wording and meaning clear?
3. Nine of the questions have instructions to go to a specific question based on your response. Did you find these instructions confusing or were they OK? (Q1, Q2, Q7, Q8, Q15, Q17, Q34, Q36, Q45.)

Thank you very much for taking part. If you wish, we will send you a copy of the report on the cognitive testing by email or in the post, whichever you prefer:

Yes, email	<input type="checkbox"/>
Yes, post	<input type="checkbox"/>
No thanks	<input type="checkbox"/>

Address:

Time2: HH:MM _____

Appendix 3: extract of cognitive interview notes log template

Date	
Planned/ED	
Start Time	

A - Letter

A1	
----	--

B - Cover Page

B1	
----	--

C - Admission

C1	
----	--

D - A&E Department

D1	
----	--

E - Ward and Q8

E1	
----	--

F -Hospital and Ward

F1	
----	--

G - Hospital Food

G1	
----	--

H - Doctors

H1	
----	--

Appendix 4: example patient scenarios

Example 1: Cognitive Testing of NPE Survey Questionnaire

Example Patient Information

Please read this information about a person who was admitted to hospital, and use it to complete the questionnaire. If information for some of the questions in the questionnaire is not included below, you can answer them any way you like.

Male, going to hospital through A&E

- Brian Carroll, aged 57, was taking down Christmas lights from his roof and fell off his ladder.
- His partner phoned for an ambulance and he was taken to the Emergency Department of his local hospital. Ambulance staff put his leg in a splint.
- Due to his severe pain and suspected broken leg, he was placed on a trolley in the Emergency Department and transferred to the Orthopaedic Unit.
- He was given pain medication and received reassurance that he would be seen as soon as possible.
- He was admitted within 5 hours, after receiving an X-ray on his left leg. He had a fractured tibia (shin bone).
- This required an operation to align the bone, which he had the following day.
- He stayed on St Brendan's Ward for three further days.
- He was seen twice by his doctor, who was nice but seemed very rushed, so he didn't ask any questions.
- He experienced a fair amount of pain, and was given pain medication every few hours. Nurses were very kind and did what they could to make him comfortable.
- He was told of his discharge time and his partner collected him.
- He was advised to watch for certain signs (pain, numbness, swelling of the left leg) and phone the hospital or return to the Emergency Department if these occurred.
- He was also told to elevate his leg when possible and how to care for the cast.
- He was shown how to use his crutches to go up and down stairs as he lived in a two-storey house.
- He was given a follow-up appointment two weeks after his discharge.

Overall, Brian's experience was positive, and he felt that the nursing staff were very kind and efficient. However, he thought that one of his medications might be causing stomach pains. When he mentioned this at discharge the nurse explained what each medication was prescribed for. She advised him to continue to take the medication along with an antacid.

Example 2: Cognitive Testing of NPE Survey Questionnaire

Example Patient Information

Please read this information about a person who was admitted to hospital, and use it to complete the questionnaire. If information for some of the questions in the questionnaire is not included below, you can answer them any way you like.

Female, going to hospital for a planned procedure

- Barbara Collins, aged 60, has a history of chest pain.
- She has been referred to her local hospital for a coronary artery bypass operation – or ‘bypass surgery’. She was admitted to the Cardiac Surgery Unit at 9am.
- After about an hour, she was taken to a bed on the ward.
- One of the nurses told her that her doctor would be doing the ward rounds at about noon.
- She saw her doctor at about 1pm and she explained the procedure to her and answered questions that she had about recovery time and pain.
- She was told to fast from that evening (but did enjoy the food that she had before that...!).
- The next morning, she was operated on under general anaesthetic, then transferred to the High Dependency Section of the ward for 24 hours, where she was monitored closely by the nurses. However, she doesn’t remember much of this.
- She stayed on the ward for a further four days. During this time, her heart rate and blood pressure were monitored regularly.
- On the second day, she was able to sit on a chair with help to get in and out of bed.
- On the third day, she had a shower with help from a nurse.
- On the fourth day, she was given an ECG, Chest X-ray, and blood tests to check that everything was OK.
- Her daughter collected her on the morning of the fifth day.
- Before she was discharged, the nurse checked that someone would be at home to care for her, and explained what activities would be safe to do.
- She also advised her to watch out for warning signs such as infection and dizziness, and how to deal with these.
- She gave her a phone number to call in case of any questions or concerns.
- She was given a follow-up appointment two weeks after discharge.
- Overall, Barbara had a very positive experience. However, she was frequently thirsty and was not offered water – she had to ring her bell to get water and felt she was annoying the nursing staff.

Appendix 5: draft invitation letter: round 1, round 2 and final

ROUND 1

Date

[Survey Code]

Dear [NAME],

National Patient Experience Survey: Invitation to Take Part

You are invited to take part in a survey about the care you received during your recent hospital stay. We are sending questionnaires to all patients that have been discharged from a public acute hospital in May 2017; your feedback is very important in helping us to understand the quality of the care you received.

Participation in the survey is voluntary and it should only take about 20 minutes to complete. If you choose not to take part, it will not affect the care you receive. None of the staff who treated you will know if you respond, and all answers are entirely confidential.

This survey is part of a national study run by the Health Service Executive (HSE), Department of Health (DoH) and Health Information and Quality Authority (HIQA). The results from the survey will be used to improve the quality of care provided to all patients. Anonymous results from the survey will be presented to the hospital where you received care as this helps the staff to understand your views. Please take this opportunity to tell us what it was like for you.

Please return the questionnaire in the FREEPOST envelope enclosed (no stamp required). If you do not want to take part, please either return the blank questionnaire or call the FREEPHONE number below. Alternatively, you can complete the survey online by visiting www.patientexperience.ie and when asked to provide your code, please enter the Survey Code at the top right hand corner of this letter.

If you would like more information, have questions on how to complete the questionnaire, or want to opt-out of this survey, please email info@patientexperience.ie or call our FREEPHONE on 1800 314 093 at no cost to yourself and we will do our best to help.

We hope you will take part. The more people that take part, the more confident we can be that the results describe the full range of patient experiences in Ireland.

Thank you.

Yours sincerely,

Tony O'Brien
Director General, HSE

ROUND 2

[Date]

Online Survey Code: [Survey Code]

Hospital Name: [Hospital Name]

Dear [Name],

National Patient Experience Survey: Help us improve our healthcare system

You are invited to take part in a survey about the care you received during your recent stay in [Hospital Name]. We are sending questionnaires to all adult patients that have been discharged from a public acute hospital in May 2017. Your feedback is very important in helping us to improve hospital care in the future.

This survey is being carried out by three national organisations: the Health Service Executive (HSE), Department of Health (DoH) and Health Information and Quality Authority (HIQA).

Participation in the survey is voluntary and it should only take about 20 minutes to complete. If you choose not to take part, it will not affect the care you receive now or in the future. None of the staff who treated you will know if you respond.

The results will be used to help make people's stay in hospital better in the future. In 2018, we will work on making improvements that you and others suggest by answering this survey. The results of the survey will be published in national reports. Hospitals will also receive feedback on the results. Your responses are anonymous and confidential. Results are always reported for groups of people, never for individuals. Your name and address are only used to send you the questionnaire and are not used for any other purpose.

Please return the completed questionnaire in the FREEPOST envelope enclosed (no stamp required), if possible within **two weeks** of receiving this letter. If you do not want to take part, please either return the blank questionnaire in the FREEPOST envelope, or call the FREEPHONE number below.

If you prefer, you can complete the survey **online** by visiting www.patientexperience.ie and using the Online Survey Code at the top right hand corner of this letter.

If you would like more information, have questions on how to complete the questionnaire, or want to opt out of this survey, please **email** info@patientexperience.ie or call our **FREEPHONE** on **1800 314093** and we will do our best to help.

We hope you will take part. The more people that take part, the more confident we can be that the results describe the full range of patient experiences in Ireland.

Thank you for taking the time to read this letter.

Yours sincerely,

Tony O'Brien

Director General, HSE

FINAL VERSION

[Date]

Survey Code: [Survey Code]

Hospital Name: [Hospital Name]

Please help us make hospital care better

Dear [Name],

You are invited to take part in a national survey about the care you received during your recent stay in [**Hospital Name**]. We are sending questionnaires to adult patients who have been discharged from a public hospital in May 2017.

Your feedback is very important and your answers will help us to make improvements to hospital care. The survey results will be published on **www.patientexperience.ie**.

Participation in the survey is voluntary and it should only take about 20 minutes. The survey is anonymous. Your individual results are never reported. Your name and address are only used to send you the questionnaire and are not used for any other purpose.

There are two ways to complete the questionnaire:

- **Online:** go to **www.patientexperience.ie** and log in with your **Survey Code** which is at the top right hand corner of this letter.
- **Freepost:** if you prefer, you can return the completed questionnaire in the Freepost envelope enclosed (no stamp needed), if possible within **two weeks** of receiving this letter.

If you would like more information or have questions on how to complete the questionnaire, please **email** us at **info@patientexperience.ie** or **call** our Freephone number on **1800 314093** (Monday-Friday, 9am-5pm) and we will do our best to help.

If you do not want to take part in this survey and would prefer not to receive a reminder letter about it, you can:

- go to www.patientexperience.ie and enter your Survey Code,
- call our Freephone number, or
- return the blank questionnaire in the Freepost envelope.

If you choose not to take part, it will not affect the care you receive now or in the future, because your answers are anonymous.

The survey is being carried out by three national healthcare organisations: the Health Service Executive (HSE), the Health Information and Quality Authority (HIQA) and the Department of Health (DoH).

We hope you will take part, because we want to improve care for all patients. The more people who take part, the more confident we can be that the results describe the full range of patient experiences in Ireland.

Thank you for taking the time to read this letter.

Yours sincerely,

Tony O'Brien

Director General

Health Service Executive (HSE)

Appendix 6: NPE Survey instrument including definitions, instructions and routing – round 1, round 2 and final

COVER PAGE (note: the text below does not include changes to font size)

ROUND 1	ROUND 2	FINAL VERSION
PATIENT QUESTIONNAIRE	PATIENT QUESTIONNAIRE Please help us improve our healthcare system	PATIENT QUESTIONNAIRE Please help us make hospital care better.
What is the survey about? The National Patient Experience Survey is a new nationwide survey asking patients about their recent experience in hospital. The purpose of the survey is to learn from patients' feedback in order to improve the planning and delivery of healthcare.	What is the survey about? The National Patient Experience Survey is a new nationwide survey asking people like you for feedback about your recent stay in hospital. The results of this survey will be used to make improvements to the quality of hospital care. Your views will make a difference.	What is the survey about? The National Patient Experience Survey is a new nationwide survey. It asks you for feedback about your most recent stay in hospital. The results of the survey will be used to improve the quality of hospital care. Your views will make a difference. Please use this survey to provide general feedback about your hospital experience. If you would like to make a comment, compliment or complaint and receive a response, please email the HSE at yoursay@hse.ie , phone 1890 424 555, or go to www.healthcomplaints.ie .
Why did I get this questionnaire? You got this questionnaire because you have spent a minimum of one night on a ward in an acute hospital, you are 18 or over and you were discharged in May 2017.	Why did I get this questionnaire? You got this questionnaire because you have spent a minimum of one night in an acute hospital, you are 18 or over, and you were discharged in May 2017.	Why did I get this questionnaire? You got this questionnaire because you spent a minimum of one night in hospital, you are 18 or over, and you were discharged in May 2017.
		Can I do the questionnaire online? Yes, please complete the survey online if possible. This can be done on a computer, smartphone or tablet at www.patientexperience.ie . However, if you prefer, you can complete this paper version of the survey and use the Freepost envelope to return it.
Do I need to fill this out myself? We would love to hear your story and that is why we encourage you to complete the questionnaire yourself. Please feel free to ask others to help you as long as the answers given are your own.	Do I need to fill this out myself? We would love to hear your story and that is why we encourage you to complete the survey yourself. Please feel free to ask others to help you as long as the answers given are your own.	Do I need to fill this out myself? No, you can ask a friend or a relative to help you once the answers given are your own.

NPE Survey: Cognitive Interviews to Finalise the Questionnaire and Invitation Letter
National Patient Experience Survey Programme

ROUND 1	ROUND 2	FINAL VERSION
<p>Completing the questionnaire</p> <p>For each question please clearly tick one box using a black or a blue pen. Sometimes you will find that the box that you have ticked will direct you to another question. By following the instructions carefully, you will be directed to the questions that apply to you.</p> <p>Please read the information in the boxes that are before some of the questions, as these give you important information to help you complete the questionnaire. Do not worry if you make a mistake; simply fill in the box ■ and put a tick <input checked="" type="checkbox"/> in the correct box.</p> <p>Please do not write your name or address anywhere on the questionnaire.</p>	<p>Completing the questionnaire</p> <p>For each question please clearly tick <input checked="" type="checkbox"/> one box using a black or a blue pen.</p> <p>Please read the information in the boxes that are before some of the questions, as these give you important information to help you complete the questionnaire. Do not worry if you make a mistake; simply fill in the box ■ and put a tick <input checked="" type="checkbox"/> in the correct box.</p> <p>Please do not write your name or address anywhere on the questionnaire.</p>	<p>Completing the questionnaire</p> <ul style="list-style-type: none"> For each question please clearly tick <input checked="" type="checkbox"/> one box using a black or a blue pen. Please read the information in the boxes that are before some of the questions, as these give you important information to help you complete the questionnaire. Do not worry if you make a mistake; simply fill in the box ■ and put a tick <input checked="" type="checkbox"/> in the correct box. There is space at the end of the questionnaire for your written comments. Please do not write your name or address anywhere on the questionnaire.
<p>Taking part in this survey is voluntary. We hope you will take part. The more people that complete and return the questionnaire, the more confident we can be that the results of the survey describe the full range of patient experiences in Ireland.</p> <p>If you have any queries about the survey or would like to opt out, please call our freephone number on 1800 314 093 or email us at info@patientexperience.ie. You can visit our website at www.patientexperience.ie. Your answers will be treated in confidence.</p>	<p>Taking part in this survey is voluntary. We hope you will take part. The more people that complete and return the questionnaire, the more confident we can be that the results of the survey describe the full range of patient experiences in Ireland.</p> <p>If you have any queries about the survey or would like to opt out, please call our FREEPHONE number on 1800 314 093 or email us at info@patientexperience.ie. You can visit our website at www.patientexperience.ie. Your answers will be treated in confidence. Your feedback will not affect your future care in any way.</p>	<p>Taking part in this survey is voluntary. We hope you will take part. The more people who complete and return the questionnaire, the more confident we can be that the results of the survey describe the full range of patient experiences in Ireland.</p> <p>If you have any questions about the survey, please call our Freephone number on 1800 314 093 (Monday-Friday, 9am-5pm) or email us at info@patientexperience.ie. You can also visit www.patientexperience.ie. To opt out of this survey, call the Freephone number or go to our website.</p> <p>Your answers will remain anonymous.</p> <p>Your feedback will not affect your future care in any way.</p>

Round 1, round 2 and final questions, instructions, definitions:

- Changes for round 2 are denoted in square brackets in red font
- Changes following round 2 are denoted in square brackets in green font
- Changes following review by the governance groups and the managed service are denoted in square brackets in blue font.

Sequence	Wording	Response options	Routing
Admission to hospital			
Instructions	Please answer all of the questions in this survey about your most recent stay in the hospital named in the letter that came with this survey. [Font size for 'most recent stay' and 'hospital named' increased] [Throughout the questionnaire, routing instructions were re-formatted from italics to bold]		
Q1	Was your most recent hospital stay planned in advance or an emergency?	Emergency or urgent; Waiting list or planned in advance; Other [Response option 2 changed to 'Planned in advance or waiting list' to better match question stem]	Yes, Q2, Q9
Q2	When you arrived at the hospital, did you go to the A&E Department (also known as the Emergency Department, Casualty, Medical or Surgical Assessment unit)? [or Surgical removed from brackets] [Reworded to: When you arrived at the hospital, did you go to the Emergency Department (also known as the A&E Department or Casualty)?]	Yes; No	Yes, Q3, Q9
The Accident and Emergency Department [The Emergency Department]			
Q3	When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could understand? [A&E Department changed to Emergency Department]	Yes, always; Yes, sometimes; No; I had no need to ask/I was too unwell to ask questions	No
Q4	While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand? [A&E Department changed to Emergency Department]	Yes, completely; Yes, to some extent; No; I did not need an explanation	No
Q5	Were you given enough privacy when being examined or treated in the A&E Department? [A&E Department changed to Emergency Department]	Yes, definitely; Yes, to some extent; No; Don't know/can't remember	No
Q6	Overall, did you feel you were treated with respect and dignity while you were in the A&E Department? [A&E Department changed to Emergency Department]	Yes, always; Yes, sometimes; No	No

Sequence	Wording	Response options	Routing
Q7	Did you remain in A&E for the entire time of your stay? [A&E Department changed to Emergency Department]	Yes, I was discharged from A&E; No, I was transferred to a different part of the hospital before I was discharged [A&E Department changed to Emergency Department]	Yes, Q8, Q53
Instructions	*If you were discharged from the A&E department , please go to page 9 and complete Q53 to 57, and provide any comments you may have on page 11. [A&E Department changed to Emergency Department]		
Definition	A ward is a room or area in the hospital where patients receive care following admission. [Added: This is where you received your care after you were moved out of A&E.] [‘following admission’ in bold; ‘you were moved out of A&E in bold.’] [A&E changed to Emergency Department]		
Q8	Following arrival at the hospital, how long did you wait before being admitted to a ward?	Less than 6 hours; Between 6 and up to 9 hours; Between 9 and up to 12 hours; Between 12 and up to 24 hours; Between 24 and up to 48 hours; More than 48 hours; Don't know/can't remember; I was not admitted to a ward [Collapsed response options 2 and 3 to ‘Between 6 and up to 12 hours’]	Yes, Q9, Q53
The Hospital and Ward			
Definition	A ward is a room or area in the hospital where patients receive care following admission. [‘following admission’ in bold]		
Instructions	If you stayed in more than one ward, please answer the following questions about the ward in which you spent most of your time.		
Q9	Were you given enough privacy when you were on the ward?	Yes, always; Yes, sometimes; No	No
Q10	In your opinion, how clean was the hospital room or ward that you were on?	Very clean; Fairly clean; Not very clean; Not at all clean	No
Q11	How clean were the toilets and bathrooms that you used in hospital?	Very clean; Fairly clean; Not very clean; Not at all clean; I did not use a toilet or bathroom	No
Q12	When you needed help from staff getting to the bathroom or toilet, did you get it in time?	Yes, always; Yes, sometimes; No; I did not need help	No
Q13	Did staff wear name badges?	Yes, all of the staff wore name badges; Some of the staff wore name badges; Very few or none of the staff wore name badges; Don't know/can't remember	No
Q14	Did the staff treating and examining you introduce themselves?	Yes, all of the staff introduced themselves; Some of the staff introduced themselves; Very few or none of the staff introduced themselves; Don't know/can't remember	No

Sequence	Wording	Response options	Routing
Hospital Food			
Q15	How would you rate the hospital food?	Very good; Good; Fair; Poor; I did not have any hospital food	Yes, Q16, Q20
Q16	Were you offered a choice of food?	Yes, always; Yes, sometimes; No	No
Q17	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc.)?	Yes; No; Don't know/can't remember	Yes, Q18, Q19
Q18	Were you offered a replacement meal at another time?	Yes, always; Yes, sometimes; No; I did not want a meal; I was not allowed a meal (e.g. because I was nil by mouth - no food or drink)	No
Q19	Did you get enough help from staff to eat your meals?	Yes, always; Yes, sometimes; No; I did not need help to eat meals	No
Doctors [Replaced with section heading 'Your Care and Treatment']			
Q20	When you had important questions to ask a doctor, did you get answers that you could understand?	Yes, always; Yes, sometimes; No; I had no need to ask	No
Q21	Did you feel you had enough time to discuss your care and treatment with a doctor?	Yes, definitely; Yes, to some extent; No	No
Nurses [Section heading deleted]			
Q22	When you had important questions to ask a nurse, did you get answers that you could understand?	Yes, always; Yes, sometimes; No; I had no need to ask	No
Q23	If you ever needed to talk to a nurse, did you get the opportunity to do so?	Yes, always; Yes, sometimes; No; I had no need to talk to a nurse	No
Your Care and Treatment [Section heading deleted]			
Q24	Were you involved as much as you wanted to be in decisions about your care and treatment?	Yes, definitely; Yes, to some extent; No	No
Q25	How much information about your condition or treatment was given to you?	Not enough; The right amount; Too much	No
Q26	Was your diagnosis explained to you in a way that you could understand?	Yes, completely; Yes, to some extent; No	No
Q27	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	Yes, definitely; Yes, to some extent; No; No family or friends were involved; My family did not want or need information; I did not want my family or friends to talk to a doctor	No

Sequence	Wording	Response options	Routing
Q28	Did you find someone on the hospital staff to talk to about your worries and fears?	Yes, definitely; Yes, to some extent; No; I had no worries or fears	No
Q29	Did you have confidence and trust in the hospital staff treating you?	Yes, always; Yes, sometimes; No	No
Q30	Were you given enough privacy when discussing your condition or treatment?	Yes, always; Yes, sometimes; No	No
Q31	Were you given enough privacy when being examined or treated?	Yes, always; Yes, sometimes; No	No
Pain			
Q32	Do you think the hospital staff did everything they could to help control your pain?	Yes, definitely; Yes, to some extent; No; I was never in any pain	No
Tests			
Definition	By tests we mean assessments, other than blood or urine tests, used to assess your needs or identify your condition. Examples of tests include: ECG, x-rays, scans. [Changed to: Tests do not include blood or urine tests. They are used to assess your needs or identify your condition. Examples of tests include: ECG, x-ray, CT scan, MRI scan, ultrasound.] [Changed to: Tests are used to assess your needs or identify your condition. They do not include blood or urine tests. Examples of tests include: ECG, x-ray, CT scan, MRI scan, ultrasound.]		
Q33	Did a doctor or nurse explain the results of the tests in a way that you could understand?	Yes, definitely; Yes, to some extent; No; Not sure/can't remember; I was told I would get the results at a later date; I was never told the results of tests; I did not have any tests	No
Treatments			
Definition	Treatments help your recovery. Examples of treatments include injection, dressing, physiotherapy.		
Q34	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen? [Deleted: '(e.g. an injection, dressing, physiotherapy)']	Yes, always; Yes, sometimes; No; I did not want an explanation; I did not have any treatments	Yes, Q35, Q36
Q35	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain any risks and/or benefits in a way you could understand? [Deleted: '(e.g. an injection, dressing, physiotherapy)']	Yes, always; Yes, sometimes; No; I did not want an explanation	No
Operations and Procedures			
Definition	Operations and procedures do not include tests and treatments. Examples of operations and procedures include: appendectomy, endoscopy, bone fracture repair, triple bypass. [Changed to: Operations and procedures do not include tests and treatments. Examples of operations and procedures include: triple bypass, repairing a broken bone with surgery, removing an appendix, hysterectomy, colonoscopy, lumbar puncture/spinal tap.] [Changed to: Examples of operations and procedures include: triple bypass surgery, repairing a broken bone with surgery, removing an appendix, colonoscopy, lumbar puncture/spinal tap.]		

Sequence	Wording	Response options	Routing
Q36	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?	Yes, completely; Yes, to some extent; No; I did not want an explanation; I did not have an operation or procedure	Yes, Q37, Q40
Q37	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?	Yes, completely; Yes, to some extent; No; I did not have any questions	No
Q38	Beforehand, were you told how you could expect to feel after you had the operation or procedure?	Yes, completely; Yes, to some extent; No	No
Q39	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?	Yes, completely; Yes, to some extent; No	No
Leaving Hospital			
Q40	Did you feel you were involved in decisions about your discharge from hospital?	Yes, definitely; Yes, to some extent; No; I did not want to be involved	No
Q41	Were you given enough notice about when you were going to be discharged?	Yes, definitely; Yes, to some extent; No	No
Q42	Were your family or someone close to you given enough notice about your discharge?	Yes, definitely; Yes, to some extent; No; No family or friends were involved; Don't know/can't remember	No
Q43	Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home? ['doctors and nurses' changed to 'healthcare staff']	Yes; No	No
Q44	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?	Yes; No	No
Q45	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?	Yes, completely; Yes, to some extent; No; I did not need an explanation; I had no medicines	Yes, Q46, Q47
Q46	Did a member of staff tell you about medication side effects to watch for when you went home?	Yes, completely; Yes, to some extent; No; I did not need an explanation	No
Q47	Did a member of staff tell you about any danger signals you should watch for after you went home?	Yes, completely; Yes, to some extent; No; It was not necessary	No

NPE Survey: Cognitive Interviews to Finalise the Questionnaire and Invitation Letter

National Patient Experience Survey Programme

Sequence	Wording	Response options	Routing
Q48	Did hospital staff take your family or home situation into account when planning your discharge?	Yes, completely; Yes, to some extent; No; Don't know/can't remember	No
Q49	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?	Yes, definitely; Yes, to some extent; No; No family or friends were involved; My family or friends did not want or need information	No
Q50	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Yes; No; Don't know/can't remember	No
Q51	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?	Yes, definitely; Yes, to some extent; No; I did not need help in managing my condition	No
Overall			
Q52	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Yes, always; Yes, sometimes; No	No
[NEW]	[Overall:]	[I had a very poor experience (0) to I had a very good experience (10)] [0-10 scale]	No
About You			
Q53	Who was the main person or people that filled in this questionnaire?	The patient (named on the front of the envelope); A friend or relative of the patient; Both the patient and the friend/relative together; The patient with the help of a health professional	No
Instructions	Reminder: All the questions should be answered from the point of view of the person names on the envelope. This includes the following questions. [Changed to: Please keep in mind that all questions...]		
Q54	Are you male or female?	Male; Female	No
Q55	What is your <u>year</u> of birth? [Underlining removed.] [Month of birth (tick-box) added, and question re-worded to 'What is your month and year of birth? (Please tick the month and write in the year)]	[Tick boxes added (January-December) to capture month of birth] 19 YY	No
Q56	What is your ethnic or cultural background? [Note added prior to Q56: We ask the next two questions because we would like to know if the people who responded to the survey represent all sections of our society.]	Irish; Irish Traveller; Any other White background; African; Any other Black background; Chinese; Any other Asian background; Other, write in description	No

Sequence	Wording	Response options	Routing
Q57a	Do you currently have a medical card and/or private health insurance? - Medical card [Changed to: Do you currently have a medical card?]	Yes; No	No
Q57b	Do you currently have a medical card and/or private health insurance? - Health insurance [Changed to: Do you currently have private health insurance?]	Yes; No	No
Q57c	Do you currently have a medical card and/or private health insurance? - No medical card or health insurance [Deleted] [Q57a and Q57b re-combined and re-worded as: Do you currently have: A medical card/Private health insurance/Both medical card and private health insurance/Neither private medical card nor private health insurance.]	Yes; No	No
Other Comments			
Instructions	<p>If there is anything else you would like to tell us about your experience in hospital, please do so here. We are interested in hearing the views and experiences of everyone, whether good or bad. Any information you provide will be treated in total confidence. Please avoid giving your own name or the names of hospital staff in your comments.</p> <p>[Changed to: Thank you very much for taking part. We are interested in hearing the views and experiences of everyone, whether good or bad. Please tell us in your own words about your hospital stay. You can use the back page of the questionnaire if you need more space. Any information you provide will be treated in total confidence.</p> <p>Please avoid giving your own name or the names of hospital staff in your comments.]</p> <p>[Changed to: Thank you very much for taking part. Please feel free to tell us below in your own words about your hospital stay. You can use the back page of the questionnaire if you need more space. Any information you provide will be treated in total confidence.</p> <p>Please avoid giving your own name or the names of hospital staff in your comments.]</p> <p>[Changed to: Thank you very much for taking part in this survey. Please feel free to tell us about your hospital stay in your own words in the boxes below. You can use the back page of the questionnaire if you need more space. Comments will be entered into a secure database after removing any information that could identify you. This anonymised feedback will be looked at by HIQA, the HSE and the Department of Health to try to understand and improve patients' experience in hospital. We will give examples of feedback in the final survey reports to provide a fuller understanding of patients' experiences.]</p>		
Q58	Was there anything particularly good about your hospital care?	Free text	No
Q59	Was there anything that could be improved?	Free text	No
Q60	Any other comments?	Free text	No