

Statement of outcomes

Patient-led focus groups for the National Patient Experience Survey

August 2016











Table of contents

| About the National Patient Experience Survey Programme 5 | | |
|--|---|--|
| 1. | Introduction and background9 | |
| 2. | Methodology 10 | |
| 2.1 | Data collection | |
| 2.2 | Breakdown of focus group11 | |
| 2.3 | Structure of the survey12 | |
| 2.4 | Data analysis13 | |
| 3. | Review Frequently asked questions (FAQ) document 14 | |
| 4. | Getting the survey out to potential participants 15 | |
| 5. | Review Survey questions | |
| 5.1 | Admission to hospital16 | |
| 5.2 | The hospital and ward | |
| 5.3 | Doctors | |
| 5.4 | Nurses | |
| 5.5 | Your care and treatment | |
| 5.6 | Operations and procedures | |
| 5.7 | Leaving hospital | |
| 5.8 | Overall theme | |
| 5.9 | About you | |
| 5.10 | Other comments | |
| 6. | Conclusion and next steps | |
| Appendix 1 — Full Library of 189 survey questions | | |
| Appendix 2 — Frequently asked questions 51 | | |
| References | | |





About the National Patient Experience Survey Programme

A partnership programme has been set up between the Department of Health (the Department), the Health Information and Quality Authority (HIQA) and the Health Service Executive (HSE) to develop and implement a survey to measure patients' experiences across the public acute healthcare services. This survey will provide a rich source of data that will contribute to improving the quality of care provided.

Department of Health

The Department of Health seeks to provide leadership and policy direction for the health sector in order to improve health outcomes and, through effective performance oversight, ensure accountability and high-quality health service delivery. Its overall aim is to improve the health and wellbeing of people in Ireland by:

- keeping people healthy
- providing the healthcare people need
- delivering high quality services and
- getting best value from health system resources.

The Department intends to establish a National Patient Safety Office (NPSO) in the Department of Health. It is intended that the NPSO will provide the required leadership and direction with regard to patient safety policy and legislation for the healthcare system. Through surveillance of patient safety trends, production of patient safety and complaints profiles, and, delivery of the national framework for clinical effectiveness it will identify, based on evidence, patient safety priorities and required patient safety initiatives.



Health Information and Quality Authority (HIQA)

HIQA is an independent authority established to drive high-quality and safe care for people using our health and social care and support services in Ireland. HIQA's role is to develop standards, inspect and review health and social care and support services, and support informed decisions on how services are delivered. HIQA's ultimate aim is to safeguard people using services and improve the quality and safety of services across its full range of functions.

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, HIQA has statutory responsibility for:

- Setting Standards for Health and Social Services Developing personcentred standards, based on evidence and best international practice, for health and social care and support services in Ireland.
- **Regulation** Registering and inspecting designated centres.
- Monitoring Children's Services Monitoring and inspecting children's social services.
- Monitoring Healthcare Quality and Safety Monitoring the quality and safety of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- Health Technology Assessment Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.
- Health Information Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care and support services.

Health Service Executive (HSE)

The HSE was established in 2005 as the single body with statutory responsibility for the management and delivery of health and personal social services to the population of Ireland. The objective of the Executive is to use the resources available to it in the most beneficial, effective and efficient manner to improve,



promote and protect the health and welfare of the population. In this regard it is responsible for the services provided by the 49 public hospitals across the State.

One of the primary goals of the HSE is to foster a culture that is honest, compassionate, transparent and accountable. Core to this goal is ensuring that people's experience of care is not only safe and of high quality, but also person centred, caring and compassionate.

Partnership approach

The partnership approach therefore fulfils and meets the remit and objectives of all of the partnership organizations, but most importantly will ensure that the patient will play the central role through representation from a patient representative or patient representatives. The survey will allow and enable patients to voice their opinion, to tell their story and, in doing so, provide a rich source of information that will assist all of the partner organizations to work towards improving the quality of patients' experience in acute healthcare.

The National Patient Experience Focus Groups

The patient-led focus groups of the National Patient Experience Survey programme had three main aims:

- 1. To ensure that the frequently asked questions (FAQ) is easily understood and answers all potential questions.
- 2. To explore possible distribution methods, that is by email, post or text.
- 3. To review and refine the library of 189 survey questions.

A focus group provides the forum to allow the participants to give their feedback on a particular product, service, concept or proposal. In this case the focus group participants reviewed the library of 189 survey questions. The focus group has a set structure with a facilitator(s) who is responsible for chairing and asking the questions, the scribe writes the notes, for larger groups the raconteur feeds back on findings for each group.

An international set of patient experience questions has been purchased for use in the National Patient Experience Survey. These questions have been tested, validated and are used in other countries. Therefore, using these questions will facilitate national and international comparison of the results of the survey, helping to ensure



that the findings will have a positive impact on the quality of care that patients in acute care services receive. These questions had been uploaded to an online tool, to enable all focus group participants to review the set of questions in advance of the focus groups meeting.

This statement of outcomes report outlines the findings from these patient-led focus groups. The feedback from focus groups on the questions to be used in the National Patient Experience Survey will now be used to refine the internationally validated survey questions to a core set of questions for Ireland. We are very grateful for the valuable contribution made by these focus groups.



1. Introduction and background

It is increasingly acknowledged that the most successful approach to building a safer and high quality healthcare system is when the health service works together with patients and communities⁽¹⁾. This collaboration ensures care that reflects the needs, wants and preferences of patients and, in the long term, results in sustainable quality improvements. Consumer participation requires a multi-pronged approach; one of these approaches involves collecting information about patients' experiences with services.

Pictured are focus group members in the Mater Misericordiae University Hospital, Dublin



The patient's voice is considered essential to inform quality improvement initiatives at a local and national level⁽²⁾.

A joint partnership programme between HIQA, the Department and the HSE has been established to put in place a plan for measuring patients' experiences across Irish healthcare services. This is called the National Patient Experience Survey Programme.

The first step in developing the survey tool was to buy internationally validated survey questions to ensure that the questions can be compared both nationally and internationally (see full list of questions in Appendix 1). In order to ensure that the questions in the National Patient Experience survey are relevant and can be understood in Ireland, six patient-led focus groups were conducted.



2. Methodology

2.1 Data collection

To support in the development of the survey, six focus groups were held across Ireland in one hospital in each of six out of the country's seven hospital groups excluding the Children's hospital. As the scope of this survey is adults in acute care, a focus group was not conducted in the Childrens Hospital Group. The purpose of these focus groups was to:

- 1. Discuss the participants' view of the frequently asked questions document (see Appendix 2 in this report).
- 2. Discuss the best way of sharing the survey with potential participants, either by email, post or text.
- 3. Examine the library of 189 internationally validated survey questions and determine which questions to include, and exclude, from the survey to ensure that it will be:
 - a. understood in an Irish context
 - b. relevant
 - c. reasonable and manageable for potential participants to complete.

Each of the focus groups comprised of representatives from six hospital groups' patient bodies. The National Patient Experience Team from HIQA availed of the opportunity of being on site to discuss the national implementation plan and answer all queries in relation to the survey with hospital staff.

The focus groups were two hours in length and conducted over a three-week period between 26 May 2016 and 10 June 2016.



Pictured are focus group members at Connolly Hospital, Dublin



2.2 Breakdown of focus group

The breakdown of the six focus group locations and the number of participants in each focus group are shown in Table 1. Each focus group participant is or has been a patient. Many of the participants are members of a patient advocacy group, which is a forum that facilitates greater engagement with patients, and it reviews and improves practices within the hospital for the patient's benefit.

Table 1. Breakdown of National Patient Experience Focus Group locations and participants

| Date in 2016 | Location | Number of participants | Number of staff met |
|--------------|---|---------------------------|---------------------------|
| 26 May | Limerick University Hospital (University of Limerick Hospitals Group) | 6 | 5 |
| 31 May | University Hospital Galway (Saolta Hospital Group) | 8 | 7 |



| Date in 2016 | Location | Number of participants | Number of staff met |
|--------------|--|---------------------------|---------------------------|
| 1 June | University Hospital Kerry (South/South West Hospital Group) | 8 | 4 |
| 3 June | St James's University Hospital, Dublin (Dublin Midland Hospital Group) | 7 | 1 |
| 8 June | Connolly University Hospital, Dublin (Royal College of Surgeons in Ireland [RCSI] Hospital Group) | 7 | 1 |
| 10 June | Mater University Hospital, Dublin (Ireland East Hospital Group) | 9 | 3 |

2.3 Structure of the survey

There are 189 questions in the survey tool that was presented to the focus groups. The questions are split up into 10 themes, and three of these themes are broken down further into sub-themes. The themes and sub-themes in the survey are outlined in Table 2.



Table 2. Structure of survey

| ID | Survey theme | Sub-theme (where applicable) |
|----|----------------------------|---|
| A | Admission to hospital | Emergency care The accident and emergency department Waiting list or planned admission All types of admission |
| В | The hospital and ward | Visitors Food |
| С | Doctors | |
| D | Nurses | |
| E | Your care and treatment | Pain Tests Treatments |
| F | Operations and procedures | |
| G | Leaving hospital | |
| н | Overall | |
| I | About you | |
| J | Other comments | |

2.4 Data analysis

All comments and suggestions from the focus groups were noted and analysed by staff members of HIQA who chaired each event. An average rating received by each survey question was taken from the findings of the six focus groups to inform the overall consensus for each question. The ratings given by the HIQA team were 'yes',



'no', 'no consensus', or 'combine' ratings. The rationale behind the ratings is outlined in Table 3.

| Rating | Rationale |
|--------------|--|
| Kating | Kationale |
| Yes | Three or more of the focus groups suggested that this question could be kept in the survey. |
| No | Three or more of the focus groups suggested that this question should be taken out of the survey. |
| No consensus | There was no general agreement among the focus groups on whether to keep, take out or combine the question. |
| Combine | Three or more of the focus groups suggested that this question should be combined with another question in the survey. |

Table 3. Rationale behind rating categories for survey questions

The feedback on each theme and sub-theme was analyzed and an overview of the findings are outlined in this report. A summary of all of the comments from the focus groups is also given in line with each theme and sub-theme.

3. Review Frequently asked questions (FAQ) document

This section will discuss the comments on the frequently asked question (FAQ) document (see Appendix 2). In particular, it will focus on language, flow, layout and overall comments.

a) Language

Suggestions made by the focus groups on the use of language include:

– ensuring the survey follows plain English guidelines



- changing the wording of question 13 from 'Can I complete the Survey Online?' to 'How do I complete the survey?'
- changing `inpatient' to `patient'
- using language that motivates patients to participate in the survey.

b) Flow

Suggestions were made to re-order the questions to allow a better flow to the document including:

- to move question 2 'Who is running the survey?' to the end of the document.
- to combine question 1 'What is the National Patient Experience Survey?' and question 3 'What is the purpose of the survey?'

c) Layout

In terms of layout for the FAQ document, the following was suggested:

- review the possibility of using a larger text size
- use less text to accommodate people with vision impairments and those with a lower level of literacy
- print FAQ document on the back of the invitation letter that will be given to patients.

d) Overall comments

The importance of proving the following information was emphasized:

- when the results of the survey would be available
- where to access the results
- how to find out what quality improvements take place as a result of findings.

4. Getting the survey out to potential participants

The focus groups discussed possible ways to distribute the survey to patients after they are discharged from the hospital. There were three potential options: email, post or a link to the survey via a text message. All of the focus groups thought that the combination of postal and email distribution methods are the most viable, as the



email option alone would not be suitable or indeed accessible to all potential participants.

Many of the focus groups did not think that the texting option would be viable, as it assumed that all participants would have a smartphone.

5. Review Survey questions

5.1 Admission to hospital

The first theme covered in the survey is admission to hospital which consists of 39 questions out of the 189 questions. The questions are split up into four sub-themes: emergency care, the accident and emergency department, waiting list or planned admission, and all types of admission.

Under this theme, topics addressed include:

- the nature of your visit
- Privacy
- availability and courtesy of hospital staff
- the ambulance services
- Information provision
- Cleanliness
- Hygiene

- waiting times
- admission process

Out of the 39 questions under the admission to hospital theme, the average ratings taken from the six focus groups show that:

- 21 of the questions were relevant to include in the survey
- nine of the questions could be taken out of the survey
- the focus group participants did not reach a consensus on seven questions, and
- it was thought that two of the questions could be combined.

The overall breakdown of admission questions are shown in Figure 1.





Figure 1. Overall breakdown of ratings of questions about admission to hospital

All of the focus groups agreed that the question 'Was your most recent hospital stay planned in advance or an emergency?' should be kept in the survey as it seeks to establish facts.

5.1.1 Emergency care

The emergency care sub-theme consists of eight questions which focus primarily on patients' experiences with the ambulance services.

The average taken from the six focus group shows that:

- five out of the eight questions were relevent to keep in the survey
- two out of the eight questions could be taken out of the survey, and
- the focus groups participants did not reach a consensus on one of the questions.

Questions regarding respect and dignity, and the overall care by ambulance services were considered a key indicator of the quality of care. It was also suggested by one of the focus groups that a scale from 1 to 10 should be used for question 9, 'Overall, how would you rate the care you received from the ambulance service?' Members of



the focus group felt this method would be very useful in allowing patients to give an accurate representation of their experiences.

Half of the focus groups commented that the wording of some of the questions, for example, question 8, 'How well do you think the ambulance service and the A&E staff worked together?' may be overly influenced by personal feelings. It was also thought that in some cases, patients using the ambulance services may have been in too much pain or in various states of unconsciousness to recall their experiences.

5.1.2 The Accident and Emergency department

The accident and emergency department (A&E) sub-theme consists of 13 questions. While the term A&E is no longer used in medical terminology, it is still used internationally and would be understood by most Irish people. These questions focus primarily on patients' experiences in the hospital emergency department.

The average taken from the six focus groups shows that:

- 9 out of the 13 questions were appropriate for the survey
- 2 out of the 13 questions could be taken out of the survey
- two of the questions could be combined into one question.

Overall, the focus group participants thought that most of the questions under this theme were relevant to keep in the survey. One focus group believed these questions were useful in highlighting the level, and approach to, communication within emergency departments. Five of the focus groups also noted that the wording should be changed from 'accident and emergency department' to 'emergency department' to fit the Irish context.

It was suggested by five of the focus groups that the timing categories in question 22, 'Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward?' should be broadened out so as to better reflect patients' experiences in Ireland. Participants suggested expanding the current longest waiting time option '8 hours and longer' to include four different options: 12 hours and longer; 24 hours and longer; 36 hours and longer; and 48 hours and longer.

It was also suggested by the focus groups that questions 19, 'In your opinion, how clean was the A&E Department?' and question 20, 'How clean were the toilets in the A&E Department?' could be combined to make one question.



Pictured are focus group members in St James's Hospital, Dublin



5.1.3 Waiting list or planned admission

The waiting list or planned admission sub-theme consists of 12 questions which focus primarily on privacy, providing information and hospital staff.

The average taken from the six focus groups shows that:

- 5 out of the 12 questions were relevant to keep in the survey
- 5 out of the 12 questions could be taken out of the survey, and
- the focus group participants did not reach a consensus on two questions.

Under this theme, the focus group participants thought that questions on providing information and on waiting times were the most important and relevant to ask in the survey. They thought that these topics seek to highlight patients' experiences with the admission process prior to being admitted to hospital.

Four of the focus groups felt that some questions such as those on the admission process to hospital could be taken out of the survey as they are not applicable to an Irish context such as for example question 23, 'When you were referred to see a specialist, were you offered a choice of hospital for your first hospital appointment?'

Focus group participants felt that within an Irish context, patients are not normally given a choice of hospital location, but are referred to hospitals that are within their catchment area. It was also suggested by two of the focus groups that the word



'treatment' should be taken out of question 30, 'Before being admitted to hospital, were you given any printed information about your condition or treatment?'

5.1.4 All types of admission

The all types of admission sub-theme consist of five questions which focus primarily on the admission process in the hospital. The average taken from the six focus groups shows that:

- one out of five questions were relevant to keep in the survey
- two out of five questions could be taken out of the survey, and
- focus groups participants did not reach a consensus on two of the questions.

The consensus amongst the focus groups was that question 39, 'How would you rate the courtesy of the staff who admitted you?' was the most important question to keep in the survey under this sub-theme. All of the focus group participants felt that this question would give an indication of patient care in hospitals. Questions on car parking facilities and the length of time it took before the patient was admitted to a ward were debated amongst the focus groups, no consensus was achieved as to whether they should or should not be included in the survey.

5.2 The hospital and ward

The second theme covered in the survey is the hospital and ward environment. The theme is split up into two sub-themes: visitors and food.

Under this theme, topics addressed include:

- privacy
- rooms or wards
- mixed-gender accommodation and bathrooms
- availability and courtesy of hospital staff
- visitors and visiting hours
- help from staff to eat meals

- noise during the day and night
- security
- information provision
- cleanliness
- quality of food



Out of the 42 questions under the hospital and ward theme, the average from the six focus groups shows that:

- 25 of the questions were relevant for the survey
- eight of the questions could be taken out of the survey
- the focus group participants did not reach a consensus on three of the questions, and
- it was thought that six of the questions could be combined.

Twenty-six questions under the hospital and ward theme focus on patients' experiences in hospital rooms and wards. The average taken from the six focus groups shows that:

- 16 out of the 26 questions should be retained in the survey
- 5 out of the 26 questions could be taken out of the survey, and
- it was thought that five of the questions could be combined.

Figure 2. Overall breakdown of ratings of questions about the hospital and ward theme



Questions on the courtesy of cleaning staff, whether help was available when a patient needed it, and whether staff introduced themselves were seen by the focus group participants as being important aspects to address in this theme. Five of the



focus groups thought that questions on the type of ward or room that the patient stayed in were irrelevant to ask.

It was also suggested by the focus groups that the four questions on noise in the wards (Qs 52–55) could be combined to make one, or two, questions. Two out of the six focus groups commented on the use of the word 'threatened' in question 59, 'Did you feel threatened during your stay in hospital by other patients or visitors?' and suggested rewording the question to make it less 'harsh'.

5.2.1 Visitors

The visitor's sub-theme consists of four questions that focus primarily on visiting hours and visitor information. The average from the six focus groups shows that:

- two out of the four questions were relevant to keep in the survey
- one out of the four questions could be taken out of the survey, and
- the focus group participants did not reach a consensus on one question.

Four of the focus groups agreed that the question on information about visiting hours should be kept in the survey, but questioned the use of the word 'rules'. Five of focus groups were in agreement that the question, 'Were you ever bothered by other patient's visitors?' was an important question to ask in the survey. The question on hand-wash gels was also debated in four of the focus groups, but it was agreed that as hand wash gels are generally well placed throughout all hospitals, this question should actually ask whether hand-wash gels are used.

Pictured are focus group members in University Hospital Kerry





5.2.2 Food

The food sub-theme consists of 12 questions that focus primarily on the choice and quality of the food available. The average from the six focus groups shows that:

- seven out of the 12 questions were relevant to keep in the survey
- two out of the 12 questions could be removed from the survey
- the focus group participants did not reach a consensus on two of the questions
- it was thought that one of the questions could be combined.



Figure 3. Breakdown of ratings of questions about the food

Overall, there was general agreement among the focus groups that most of the survey questions on food were highly relevant. All of the focus groups were in agreement that the question on whether or not help was available to patients on the wards to help patients eat their meals was the most important question to ask. It was also suggested by two out of the six focus groups that some of the questions in this sub-theme could be repositioned to help with improve the flow of the questions.

5.3 Doctors

The third theme covered in the survey is about patients' experiences with the doctors they meet, which consists of nine questions out of the total 189 questions.

Under this theme, topics addressed include:

- information provided and answers to questions
- availability of doctors



- courtesy of doctors
- confidence and trust in doctors.

Out of the nine questions under the doctors' theme, the average taken from the six focus groups shows that:

- five out of the nine questions were relevant to include in the survey
- one out of the nine questions could be taken out of the survey
- the focus group participants did not reach agreement on three questions.



Figure 4. Overall breakdown of ratings of questions about doctors

The overall consensus among the focus groups was that communication between doctors and patients is an important aspect of patients' experiences in hospital. It was suggested by four of the groups that some of the questions may need to be reworded to remove their subjectivity such as for example question 86, 'Did you have confidence and trust in the doctors treating you?'

5.4 Nurses

The fourth theme covered in the survey is patients' experiences with nurses, which consists of eight questions out of the 189.



Under this theme, topics addressed include:

- providing information and answers to questions
- availability and courtesy of nurses
- confidence and trust in nurses.





Out of the eight questions under the nurses theme, the average taken from the six focus groups shows that:

- six out of the eight questions were appropriate to include in the survey
- the focus group participants did not reach general agreement on two questions.

Under this theme, the focus group participants all believed these questions were important to ask as they would indicate the level of communication between patients and nurses in the hospital. The participants also highlighted the findings from the answers to these questions may generate useful information for hospitals to capture in terms of providing insights into activity in hospitals and therefore help hospitals to plan their budgets and staffing. They felt the responses will also inform hospital approaches to communication.



5.5 Your care and treatment

The fifth theme covered in the survey is your care and treatment, which consists of 32 questions. The questions are split up into three sub-themes: pain, tests and treatments.

Under this theme, topics addressed include:

- providing information
- family involvement
- privacy
- calling for help using the callbutton
- treatments

- involvement in decisions
- emotional support
- pain management
- tests

Out of the 32 questions under the theme of your care and treatment, the average taken from the six focus groups shows that:

- 18 out of the 32 questions were appropriate for the survey
- 10 out of the 32 questions could be taken out of the survey
- the focus group participants did not reach a consensus on four questions.

The 12 questions under this theme focus primarily on patients' involvement in their own care and treatment, and information given to them about their care and treatment.

The average taken from the six focus groups shows that:

- 8 out of the 12 questions were relevant to keep in the survey
- 1 out of the 12 could be removed from the survey, and
- the focus group participants did not reach general agreement on three questions.





Figure 6. Overall breakdown of ratings of questions about your care and treatment theme

Topics that were considered to be particularly important under this theme were privacy, the communication between staff members and patients, and patients' involvement in their own care and treatment. All of the focus groups were in agreement that questions on these topics were relevant to keep in the survey as they were important aspects of patients' experiences.

Five of the focus groups thought that questions in relation to hospital gowns could be removed from the survey as they believed it was common practice that all patients wear hospital gowns when staying in a hospital.

5.5.1 Pain

The pain sub-theme consists of nine questions which focus primarily on pain management. The average from the six focus groups shows that:

- three out of the nine questions were relevant to keep in the survey, and
- six out of the nine questions could be removed from the survey.



Overall, the focus groups agreed that pain management and the waiting time for medication after pain relief medication had been requested were the most important information to capture in this theme. The focus group participants queried whether some of the questions, particularly those that asked about the severity of the pain (that is to say, mild, moderate or severe) and self-medication, were subjective and contradicted one another. They suggested that these questions should be reworded or taken out of the survey.

5.5.2 Tests

The tests sub-theme consists of five questions which focus primarily on tests that the patient may have undergone while in hospital. The average from the six focus groups shows that:

- four out of the five questions were appropriate for the survey, and
- one out of the five questions could be removed from the survey.

Overall, the focus groups agreed that most of the questions under this sub-theme were relevant. One of the focus groups commented on the time aspect of the questions and thought that this would be very useful information for hospitals to capture. Half of the focus groups believed the question on the effectiveness of staff communicating the results of the tests to the patients could be taken out of the survey as this information is captured under other themes.

5.5.3 Treatments

The treatments sub-theme consists of six questions which focus primarily on treatments the patient may have undergone while in hospital.

The average from the six focus groups shows that:

- three out of the six questions were relevant to retain in the survey
- two out of the six questions could be removed
- the focus group participants did not reach a consensus on one question.

All of the focus groups agreed that question 127, 'Did you feel you could refuse any treatment that you did not agree with or did not want?' was a very important question to keep in the survey as it addressed the issue of consent and patient care.



On the topic of medical students, four of the focus groups felt that the question on whether you were asked permission for medical student to be present was the most important question to ask, and the other two questions relating to medical students could be taken out of the survey.



Pictured are focus group members in University Hospital Kerry

5.6 Operations and procedures

The sixth theme covered in the survey is operations and procedures, which consists of nine out of the 189 questions.

Under this theme, topics addressed include:

- providing information
- communication before the operation or procedure
- administration of medication
- communication after the operation or procedure.

Out of the nine questions under this theme, the average taken from the six focus groups shows that:

- seven out of the nine questions were relevant to keep in the survey
- two out of the nine could be taken out of the survey.





Figure 7. Overall breakdown of ratings of questions about the operations and procedures theme

Under this theme, all of the focus groups agreed that most of the questions should be included as they focus on the level and effectiveness of communication between staff and patients both before and after an operation or procedure. Four of the focus groups questioned if asking patients whether or not they had received an anaesthetic or medication before an operation was relevant, as they queried whether a patient would accurately remember this information.

5.7 Leaving hospital

The seventh theme covered in the survey is leaving hospital which consists of 28 questions out of the total 189 questions.

Under this theme, topics addressed include:

- patient's involvement in decisions about their care
- providing information
- post-hospital visit
- care or assistance after leaving hospital
- family involvement
- discharge from hospital
- copies of medical letters



Out of the 28 questions under the leaving hospital theme, the average taken from the six focus groups shows that:

- 24 out of the 28 questions were relevant to keep in the survey
- four out of the 28 questions could be removed.

Figure 8. Overall breakdown of ratings of questions about the leaving hospital theme



Questions on the communication between staff and patients in relation to medication and aftercare, and patients' involvement in their discharge decisions were noted by the focus group participants as being very important. One of the focus groups believed that this information would be very useful for hospitals because it could be used for discharge planning.

Four of the focus groups thought that questions relating to medical letters between the patient and their family doctor could be taken out of the survey as it was felt this is not common practice in an Irish context and would be dependent on the type of patient and their needs.

It was also suggested by one of the focus group that examples should be given in question 165, 'After leaving hospital, do you think you received enough care and



assistance from health and social services?' so that patients, or family members and or friends, can clearly understand what is meant by health and social services.

5.8 Overall theme

The eighth theme covered in the survey is called 'Overall'. It consists of eight questions out of the 189 questions.

Under this theme, topics addressed include:

- respect and dignity
- overall experience
- complaints.

Out of the eight questions under the overall theme, the average taken from the six focus groups shows that:

- six out of the eight questions were relevant
- one out of the eight questions could be removed
- the focus group participants did not reach a consensus on one question.



Figure 9. Overall breakdown of the overall theme



Under this theme, all of the focus groups agreed that it was very important to keep questions relating to respect, dignity and overall experience in the survey. The focus group participants commented that they liked the rating scale that was used in the overall experience question, and they noted that this method would be very useful in allowing patients to give an accurate representation of their experiences.

Questions on the complaint system in hospitals also rated quite highly in the focus groups, with four of the focus groups agreeing that they should be kept in the survey. However, it was suggested by one focus group that a question along the lines of, 'I was afraid to complain as I thought it would affect my treatment' could be added in as an option as it was felt some patients may be scared to make a complaint.

5.9 About you

The ninth theme covered in the survey is 'About You' which consists of 11 questions out of the total 189 questions.

Under this theme, topics addressed include:

- age
- gender
- ethnicity
- religion.

Out of the 11 questions under the About You theme, the average taken from the six focus groups shows that:

- 4 out of the 11 questions were relevant to keep in the survey
- 4 out of the 11 could be removed from the survey
- the focus group participants did not reach a consensus on three questions.





Figure 10. Overall breakdown of ratings of questions about the about you theme

Under this theme, four of the focus groups agreed that questions relating to the age and gender of the patients were relevant for information gathering purposes. For the age-related question, it was suggested by the focus group participants that age categories (for example, 18–25 years) would be more appropriate to use rather than asking patients to state the date of their birth. It was felt that this would also encourage more patients to offer this information.

It was agreed by five of the focus groups that the ethnicity, religion, sexuality, and educational attainment questions could be removed. The language used in this theme was also discussed in-depth and there was a consensus among all of the focus groups that if the questions remained in the survey, then the language should be changed to reflect the wording used in the Irish census.

5.10 Other comments

The tenth and final theme consists of three questions providing the patient with the opportunity to comment in their own words on aspects of their care that were particularly good and on aspects of their care that could have been better.



6. Conclusion and next steps

In conclusion, the six focus groups believed that out of the 189 questions in the internationally validated tool, 119 questions could be kept in the National Patient Experience Survey; 39 questions could be removed; no consensus was reached on 23 questions; and eight questions could be combined.

Each focus group participant and organizer was enthusiastic and engaged in the survey. The importance of conducting this survey was acknowledged and welcomed by all of the Focus Groups. While time and effort has been dedicated to the focus groups and detailing the findings, this exercise has informed and strengthened the survey.



Figure 11. Overall breakdown of ratings of questions about the survey

The next steps involved in the project will be to undertake what is called a 'Delphi Study' which will start in September 2016. The objective of the Delphi Study is to refine the 189 questions to a core set of questions for the Irish survey. The feedback from focus groups will be incorporated into the Delphi Study.



Acknowledgements

The partnership organizations (HIQA, the Department of Health and the HSE) welcomed all contributions and would like to thank all of focus group participants, the Patient Council Coordinators and all members of hospital staff who met with the National Patient Experience team for their comments and suggestions on the National Patient Experience Survey.


Appendix 1 — Full Library of 189 survey questions

Admission to hospital theme

| 1. | Was your most recent hospital stay planned in advance or an emergency? |
|-----|--|
| 2. | Did you travel to the hospital by ambulance? |
| 3. | Were the ambulance crew reassuring? |
| 4. | Did the ambulance crew explain your care and treatment in a way you could understand? |
| 5. | Did the ambulance crew do everything they could to help control your pain? |
| 6. | Overall, did the ambulance crew treat you with respect and dignity? |
| 7. | Once you had arrived at hospital, how long did you wait with the ambulance crew before your care was handed over to the A&E staff? |
| 8. | How well do you think the ambulance service and A&E staff worked together? |
| 9. | Overall, how would you rate the care you received from the ambulance service? |
| 10. | When you arrived at the hospital, did you go to the A&E Department? |
| 11. | While you were in the A&E Department, how much information about your condition or treatment was given to you? |
| 12. | Were you given enough privacy when being examined or treated in the A&E Department? |
| 13. | When you had important questions to ask doctors and nurses in the A&E Department, did you get answers that you could |



| | understand? |
|-----|---|
| 14. | While you were in the A&E Department, did you have confidence and trust in the doctors and nurses examining and treating you? |
| 15. | While you were in the A&E Department, did doctors or nurses talk in front of you as if you weren't there? |
| 16. | While you were in the A&E Department, did a doctor or nurse explain your condition and treatment in a way you could understand? |
| 17. | If you had any worries or fears about your condition or treatment, did a doctor or nurse discuss them with you? |
| 18. | Were hand-wash gels available for patient and visitors to use? |
| 19. | In your opinion, how clean was the A&E Department? |
| 20. | How clean were the toilets in the A&E Department? |
| 21. | Overall, did you feel you were treated with respect and dignity while you were in the A&E Department? |
| 22. | Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward? |
| 23. | When you were referred to see a specialist, were you offered a choice of hospital for your first hospital appointment? |
| 24. | How do you feel about the length of time you were on the waiting list before your admission to hospital? |
| 25. | When you were told you would be going into hospital, were you given enough notice of your date of admission? |
| 26. | Were you given a choice of admission dates? |
| 27. | Was your admission date changed by the hospital? |
| 28. | In your opinion, had the specialist you saw in the hospital been |
| | |



| | given all of the necessary information about your condition or illness from the person who referred you? |
|-----|---|
| 29. | Before being admitted to hospital, were you given any printed information about the hospital? |
| 30. | Before being admitted to hospital, were you give any printed information about your condition or treatment? |
| 31. | Before you arrived at the hospital, were you told where you would have to go to be admitted? |
| 32. | Once you arrived at the hospital, was it easy to find your way to the main reception? |
| 33. | Was it easy to find your way to the ward? |
| 34. | Before you arrived at the hospital, did you know if a bed was definitely available for you? |
| 35. | Was it possible to find a convenient place to park in the hospital car park? |
| 36. | How organised was the admission process? |
| 37. | From the time you arrived at the hospital, did you feel that you had to wait a long time to get to a bed on a ward? |
| 38. | Did a member of staff explain why you had to wait? |
| 39. | How would you rate the courtesy of the staff who admitted you? |

The hospital and ward environment theme

| 40. | While in hospital, did you ever stay in a critical care area (e.g. |
|-----|--|
| | Intensive Care Unit, High Dependency Unit or Coronary Care |



| | Unit)? |
|-----|---|
| 41. | When you were first admitted to a bed on a ward, did you share a sleeping area, for example a room or bay, with patients of the opposite sex? |
| 42. | When you were first admitted, did you mind sharing a sleeping area, for example a room or bay, with patients of the opposite sex? |
| 43. | During your stay in hospital, how many wards did you stay in? |
| 44. | Did you mind being moved from one room or ward to another? |
| 45. | After you moved to another ward (or wards), did you ever share a sleeping area, for example a room or bay, with patients of the opposite sex? |
| 46. | While in hospital, did you ever use the same bathroom or shower area as patients of the opposite sex? |
| 47. | When you needed to use a toilet or bathroom, was there a suitable one located close by? |
| 48. | When you needed help from staff getting to the bathroom or toilet, did you get it in time? |
| 49. | For most of your stay, what type of room or ward were you in? |
| 50. | When you reached the ward, did you get enough information about ward routines, such as timetables and rules? |
| 51. | Were you given enough privacy while you were on the ward? |
| 52. | Were you ever bothered by noise during the day from other patients? |
| 53. | Were you ever bothered by noise during the day from hospital staff? |
| 54. | Were you ever bothered by noise at night from other patients? |
| P | |



| 55. | Were you ever bothered by noise at night from hospital staff? |
|-----|---|
| 56. | In your opinion, how clean was the hospital room or ward that you were in? |
| 57. | How clean were the toilets and bathrooms that you used in hospital? |
| 58. | How would you rate the courtesy of the cleaning staff? |
| 59. | Did you feel threatened during your stay in hospital by other patients or visitors? |
| 60. | Did you have somewhere to keep your personal belongings whilst on the ward? |
| 61. | Did staff wear name badges? |
| 62. | Did the staff treating and examining you introduce themselves? |
| 63. | Did you find it easy to find your way around the hospital? |
| 64. | If you needed help from a hospital porter to get around the hospital did you get it? |
| 65. | How would you rate the courtesy of the hospital porters? |
| 66. | Were the visiting times convenient for your friends and family? |
| 67. | Were your visitors given enough information about visiting (e.g. visiting hours and rules)? |
| 68. | Were hand-wash gels available for patients and visitors to use? |
| 69. | Were you ever bothered by other patients' visitors? |
| 70. | How would you rate the hospital food? |
| 71. | Was the hospital food appetising? |
| 72. | Was there healthy food on the hospital menu? |
| r. | |



| 73. | How much food were you given? |
|-----|--|
| 74. | Were you offered a choice of food? |
| 75. | Did you get the food you ordered? |
| 76. | Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)? |
| 77. | Was the hospital food suitable for your dietary needs? |
| 78. | Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc.)? |
| 79. | Were you offered a replacement meal at another time? |
| 80. | Did you get enough help from staff to eat your meals? |
| 81. | How would you rate the courtesy of the catering staff? |
| | |

Doctors' theme

| 82. | Was there one doctor in overall charge of your care? |
|-----|--|
| 83. | When you had important questions to ask a doctor, did you get answers that you could understand? |
| 84. | If you had any worries or fears about your condition or treatment, did a doctor discuss them with you? |
| 85. | Did you feel you had enough time to discuss your care and treatment with a doctor? |
| 86. | Did you have confidence and trust in the doctors treating you? |
| 87. | Did doctors talk in front of you as if you weren't there? |
| 88. | If you ever needed to talk to a doctor, did you get the opportunity to do so? |



| 89. | How would you rate the courtesy of your doctors? |
|-----|---|
| 90. | In your opinion, did the doctors who treated you know enough about your condition or treatment? |

Nurses' theme

| 91. | When you had important questions to ask a nurse, did you get answers that you could understand? |
|-----|---|
| 92. | If you had any worries or fears about your condition or treatment, did a nurse discuss them with you? |
| 93. | Did you have confidence and trust in the nurses treating you? |
| 94. | Did nurses talk in front of you as if you weren't there? |
| 95. | In your opinion, were there enough nurses on duty to care for you in hospital? |
| 96. | If you ever needed to talk to a nurse, did you get the opportunity to do so? |
| 97. | How would you rate the courtesy of your nurses? |
| 98. | In your opinion, did the nurses who treated you know enough about your condition or treatment? |

Your care and treatment theme

| 99. | Sometimes in a hospital a member of staff will say one thing and another will say something quite different. Did this happen to you? |
|------|--|
| 100. | Were you involved as much as you wanted to be in decisions about your care and treatment? |
| 101. | How much information about your condition or treatment was given to you? |



| 102. While you were in hospital, were you told your diagnosis? (explanation of what was wrong with you) 103. Was your diagnosis explained to you in a way that you could understand? 104. If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so? 105. Did you find someone on the hospital staff to talk to you about your worries and fears? 106. Did you feel you got enough emotional support from hospital staff during your stay? 107. Did you have to wear a hospital gown at any point during your stay in hospital? 108. Did you have to spend time in an area with other patients while wearing the gown? 109. Were you given enough privacy when discussing your condition or treatment? 110. Were you ever in any pain? 112. When you had pain, was it usually severe, moderate or mild? 113. During your stay in hospital, how much of the time were you in pain? 114. Did you ever request pain relief medication? 115. How many minutes after you requested pain relief medication did it usually take before you got it? 116. While you were in hospital, were you given any medicine to help with your pain (such as tablets, a spray or pump) which you could decide when to take without having to ask hospital staff? | | |
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| 103. Was your diagnosis explained to you in a way that you could understand? 104. If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so? 105. Did you find someone on the hospital staff to talk to you about your worries and fears? 106. Did you feel you got enough emotional support from hospital staff during your stay? 107. Did you have to wear a hospital gown at any point during your stay in hospital? 108. Did you have to spend time in an area with other patients while wearing the gown? 109. Were you given enough privacy when discussing your condition or treatment? 110. Were you ever in any pain? 112. When you had pain, was it usually severe, moderate or mild? 113. During your stay in hospital, how much of the time were you in pain? 114. Did you ever request pain relief medication? 115. How many minutes after you requested pain relief medication did it usually take before you got it? 116. While you were in hospital, were you given any medicine to help with your pain (such as tablets, a spray or pump) which you could | 102. | While you were in hospital, were you told your diagnosis? |
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| | 116. | with your pain (such as tablets, a spray or pump) which you could |



| Do you think the hospital staff did everything they could to help control your pain? Overall, how much pain relief medication did you get? How many minutes after you used the call button did it usually take before you got the help you needed? During your stay in hospital, did you have any tests, x-rays, or scans other than blood or urine tests? Were you told in advance when your tests, X-rays or scans were going to take place? Were your scheduled tests, X-rays or scans performed on time? Did a member of staff explain why the scheduled tests were not performed on time? Did a doctor or nurse explain the results of the tests in a way that you could understand? 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? Did you feel you could refuse any treatment that you did not agree with or did not want? Were you asked for permission for medical students to be present when you were being treated or examined? Were you upset because medical students were present? | | |
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| examined? 129. Were you asked for permission for medical students to be present when you were being treated or examined? | 127. | |
| when you were being treated or examined? | 128. | · · · - |
| 130. Were you upset because medical students were present? | 129. | |
| | 130. | Were you upset because medical students were present? |



Operations and procedures theme

| 131. | During your stay in hospital, did you have an operation or procedure? |
|------|---|
| 132. | Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand? |
| 133. | Beforehand, did a member of staff explain what would be done during the operation or procedure? |
| 134. | Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand? |
| 135. | Beforehand, were you told how you could expect to feel after you had the operation or procedure? |
| 136. | Did you have enough time to discuss your operation or procedure with the consultant? |
| 137. | Before the operation or procedure, were you given an anaesthetic or medication to put you to sleep or control your pain? |
| 138. | Before the operation or procedure, did the anaesthetist or another member of staff explain how he or she would put you to sleep or control your pain in a way you could understand? |
| 139. | After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand? |
| | |

Leaving hospital theme

| 140. | Did you feel you were involved in decisions about your discharge from hospital? |
|------|---|
| 141. | Were you given enough notice about when you were going to be discharged? |



| 142. | Were your family or someone close to you given enough notice about your discharge? |
|------|--|
| 143. | On the day you left hospital, was your discharge delayed for any reason? |
| 144. | What was the MAIN reason for the delay? |
| 145. | How long was the delay? |
| 146. | Did a member of staff tell you how long the delay would be? |
| 147. | Did a member of staff explain the reason for the delay? |
| 148. | Where did you spend your time waiting to be discharged from hospital? |
| 149. | Before you left hospital, did the doctors and nurses spend enough time explaining about your health and care after you arrive home? |
| 150. | Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital? |
| 151. | Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand? |
| 152. | Did a member of staff tell you about medication side effects to watch for when you went home? |
| 153. | Were you told how to take your medication in a way you could understand? |
| 154. | Were you given clear written or printed information about your medicines? |
| 155. | Did a member of staff tell you about any danger signals you should watch for after you went home? |
| 156. | Did hospital staff take your family or home situation into account |



| | when planning your discharge? |
|------|---|
| 157. | Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you? |
| 158. | Did hospital staff tell you when you could resume your usual activities, such as when to go back to work or drive a car? |
| 159. | Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital? |
| 160. | Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital? |
| 161. | Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector.) |
| 162. | Do you feel that you received enough information from the hospital on how to manage your condition after your discharge? |
| 163. | Did hospital staff give you information about voluntary and support groups for people who have a similar condition in your local area? |
| 164. | Did hospital staff give you information about any government assistance, such as benefits, tax breaks or home care, for people in your situation or with your condition? |
| 165. | After leaving hospital, do you think you received enough care and assistance from health or social services? |
| 166. | Did you receive copies of letters sent between hospital doctors and your family doctor (GP)? |
| 167. | Were the letters written in a way that you could understand? |



Overall theme

| 168. | Overall, did you feel you were treated with respect and dignity while you were in the hospital? |
|------|---|
| 169. | Overall, were you treated with kindness and understanding while you were in the hospital? |
| 170. | Overall (Please rate) |
| 171. | During your hospital stay, were you ever asked to give your views on the quality of your care? |
| 172. | Did you see, or were you given, any information explaining how to complain to the hospital about the care you received? |
| 173. | Did you want to complain about the care you received in hospital? |
| 174. | Did hospital staff give you the information you needed to do this? |
| 175. | During your hospital stay, do you feel that you were treated unfairly for any of the reasons below? |

About you theme

| 176. | Who was the main person or people that filled in this questionnaire? |
|------|--|
| 177. | Are you male or female? |
| 178. | What was your year of birth? |
| 179. | Do you have any of the following longstanding conditions? |
| 180. | Does this condition(s) cause you difficulty with any of the following? |
| 181. | What is your ethnic group? |



| 182. | What is your religion? |
|------|--|
| 183. | Were your religious beliefs respected by the hospital staff? |
| 184. | Were you able to practise your religious beliefs in the way you want to in hospital? |
| 185. | Which of the following best describes how you think of yourself? |
| 186. | How old were you when you left full-time education? |

Other comments

| 187 | Was there anything particularly good about your hospital care? |
|-----|--|
| 188 | Was there anything that could be improved? |
| 189 | Any other comments? |





Appendix 2 — Frequently asked questions

1. What is the National Patient Experience Survey?

The National Patient Experience Survey is a way of learning about people's experience as inpatients in acute care hospitals in Ireland.

2. Who is running the survey?

The Health Information and Quality Authority (HIQA), the Department of Health and the Health Service Executive (HSE) are working together to develop and implement the National Patient Experience Survey. HIQA is the lead partner.

3. What is the purpose of the survey?

The survey aims to improve the quality of care in Irish hospitals by learning from the experience of patients. International evidence suggests that listening to the patient's voice is the best way of improving the safety and quality of healthcare.

4. What is the scope of the survey?

The first survey will focus on your experience as an inpatient in an acute care hospital.

5. When will the survey be launched?

The survey will be launched in 2017. Everyone inpatient during a specified period of time during that year will receive a letter or an email from the HSE asking them to participate.

6. What are the benefits of the survey for me?

The survey offers you the opportunity to tell us about your experience in hospital. This information will help HIQA, the Department of Health and the HSE to improve the quality of services provided to patients.



7. What will you do with my answers?

Your answers will provide us with information on the quality and safety of care in the Irish healthcare system. All participating hospitals will be able to compare their performance with other hospitals and make any necessary improvements. All responses are anonymous and will be kept on file for eight years.

8. I had a good experience in hospital; do I still need to take part?

If you received good quality care, then you can use the survey as an opportunity to let hospital staff know that you were happy with your experience.

9. Can I give the survey to a family member or friend to fill in?

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 with the survey as long as the answers you give are your own.

10. What type of questions will I be asked?

The questions will cover all aspects of your stay in hospital, for example, your admission, the ward you stayed on, the quality of care, the food and your discharge.

11. Is the survey anonymous?

Yes. You will not be asked to provide any personal information in the survey. Your contact details such as your name and address will be deleted from the HSE database a maximum of six weeks after we first contact you.

12. Can I complete the Survey in any other languages?

The survey can also be completed in Irish.

13. Can I complete the survey online?

Yes. The survey can be completed online or on a printed paper form.

14. Where can I find out more?

More information on the National Patient Experience Survey can be found on www.hiqa.ie.



References

- (1) Wilson T, Devlin J. *Costs and Benefits of Implementing a Patient Experience Strategy; Or Why Every Director of Finance Should be Investing in Patient Experience* [Online]. Accessed on: 29 June 2015.
- (2) Health Information and Quality Authority. *International review on the use of information for the regulation of health and social care*. 2014. Accessed on: 10 June 2015.









Notes