

# National Patient Experience Survey

# Technical Report

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## About the National Patient Experience Survey 2017

The National Patient Experience Survey is a new nationwide survey asking people for feedback about their recent stay in hospital. The survey is a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

All adult patients discharged during May 2017 who spent 24 hours or more in any of the participating 40 public acute hospitals and had a postal address in the Republic of Ireland were invited to complete the survey. Paediatric services, maternity services, psychiatric services, children under 18 and stays of under 24 hours were not included in the 2017 survey.

Approximately two weeks after discharge, patients were sent an invitation letter in the post, with a copy of the survey questionnaire, which they could complete on paper or online. The 2017 survey closed on 26 July 2017.

The questionnaire consisted of 58 structured questions and three qualitative free-text questions. It asked about admission to hospital, the emergency department, the hospital and ward, hospital food, care and treatment, tests, operations and procedures, leaving hospital, overall experience, and also contained demographic questions about respondents. It included three open-ended questions asking for written comments about what was good about the care received, and what might be improved (refer to Appendix 1 for a list of the survey questions).

The results of the survey were published in December 2017. The national, hospital group and hospital reports can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

This survey is part of a broader programme to help improve the quality and safety of healthcare services provided to patients in Ireland.

# Purpose and content of the National Patient Experience Survey technical report 2017

## Purpose of the report

This report provides a comprehensive technical description of the methods and procedures implemented for each major phase of the National Patient Experience Survey 2017. This report has been designed to provide sufficient detail for repetition, replication, and review of the adopted survey model and methodology.

## Content of this report

This report consists of seven chapters. A brief synopsis of each is provided below.

**Chapter one** provides an introduction to the National Patient Experience Survey. It outlines the rationale for the project and describes the survey methodology.

**Chapter two** details the exploratory and model design phase of the National Patient Experience Survey. It details the preparatory processes initiated to ensure compliance with data protection requirements. It describes the development of the survey tool as well as the methods of engagement with participating hospitals.

**Chapter three** describes the testing phase which was conducted in March and April 2017, which sought to assess the fitness for purpose of the sampling routines, the survey administration process, the helpline and email support procedures.

**Chapter four** provides an overview of the survey implementation phase. It summarises operational and sampling outcomes. It also provides information on the number and type of queries received by the information helpline.

**Chapter five** describes the data processing and analysis phase of the survey. It provides an overview of the quantitative and qualitative methodologies employed in analysing patient experience data, as well as quality assurance processes related to this data.

Lastly, **chapter six** describes the reporting outputs.

This document does not report on the survey results. The reports of the survey findings can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

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# 1. Introduction

## 1.1. The National Patient Experience Survey

The National Patient Experience Survey is the first of its kind in Ireland. It gives patients an opportunity to describe their experiences during their recent stay in hospital, with a view of using this information to improve Ireland's health service. It is organised by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. The inpatient survey took place, for the first time, in 2017 and will be repeated annually.

Patients were asked 61 questions about their journey through hospital. The survey questions originate from a library of internationally-validated questions developed by the Picker Institute in the United States<sup>(1)</sup>. A total of 26,635 individuals were invited to participate in the survey, of which 13,706 returned a questionnaire. The last surveys were accepted on 26 July. 90% of respondents returned the survey questionnaire in the post, with 10% filling it in online.

The results of the survey were published in December 2017. The national, six hospital group and 39 hospital reports<sup>1</sup> are available to download from [www.patientexperience.ie](http://www.patientexperience.ie).

## 1.2. Rationale for the survey

Positive patient experience is routinely associated with improved patient safety and more efficient clinical care.<sup>(2)</sup> Patient perspectives can add important insights into the organisation of various healthcare settings.<sup>(2)</sup> For these reasons, HIQA, the HSE and the Department of Health have committed to using data collected from the survey to shape future healthcare policy and ensure better patient-centred care and outcomes for patients.

The 2017 National Patient Experience Survey provides an important baseline to inform the design of quality improvement initiatives for a strong patient safety culture in the Irish health service. Regulators can use this information to benchmark patient experiences against national healthcare standards. Future repetitions of the survey will permit evaluations of improvements to care over time. The survey will also allow for a comparison of patient experience with other jurisdictions.

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<sup>1</sup>Even though 40 hospitals participated in the survey in 2017, only 39 hospital reports will be produced. Our Lady of Lourdes Hospital in Drogheda and Louth County Hospital in Dundalk asked for their results to be merged to ensure a sufficient response rate was achieved.

### 1.3. Management of the National Patient Experience Survey

An international review, conducted in 2016 by HIQA, found that in the jurisdictions reviewed, national patient experience surveys are implemented in partnership between healthcare regulators, service providers and policymakers. Projects involving multiple entities with a stake in patient experience improvement ensure that findings are leveraged appropriately across the healthcare sector. A partnership approach was thus adopted in the roll-out of the National Patient Experience Survey Programme in Ireland.

HIQA, as the lead partner, contracted a managed service to administer the 2017 survey and process the responses received. In 2017, the managed service was responsible for:

- receiving and quality assuring the lists of sampled persons from participating hospitals
- printing and distributing the questionnaire
- logging returns, opt-outs and ineligible respondents
- providing information to respondents on a dedicated survey helpline
- data processing and quality assuring of the survey responses
- the design of a public-facing website for the National Patient Experience Survey
- the hosting of a secure back-end database to allow hospitals to view the results of their performance in the survey in an online reporting platform (survey dashboard<sup>2</sup>) in advance of the publication of the results.

### 1.4. Survey design

#### 1.4.1. Survey methodology


The National Patient Experience Survey is based on a concurrent mixed-mode response design, which allows participants to complete the survey online or by returning a paper-based questionnaire in the post. The mode of contact, however, is via post only. Participants receive a survey pack in the post two weeks after discharge from hospital. The invitation letter provides recipients with the choice of completing the survey online or on paper.

The administration of two reminder letters was built into the survey design. One or two reminder letter(s) were sent to people who had not yet returned a survey. Internationally, the second reminder has been shown to increase response rates significantly.<sup>(3)</sup>

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<sup>2</sup> The survey dashboard was customised to the specific reporting requirements of the National Patient Experience Survey. More information on the reporting platform/survey dashboard is presented in Chapter 6.

Participants were also given the option to opt-out of the survey. Five opt-out methods were provided, one in the hospital and four after discharge:

- 
- 1** Opt-out at discharge while still in hospital.
  - 2** Opt-out by calling the Freephone number.
  - 3** Opt-out by emailing [info@patientexperience.ie](mailto:info@patientexperience.ie)
  - 4** Opt-out-online on [www.patientexperience.ie](http://www.patientexperience.ie)
  - 5** Return a blank questionnaire.

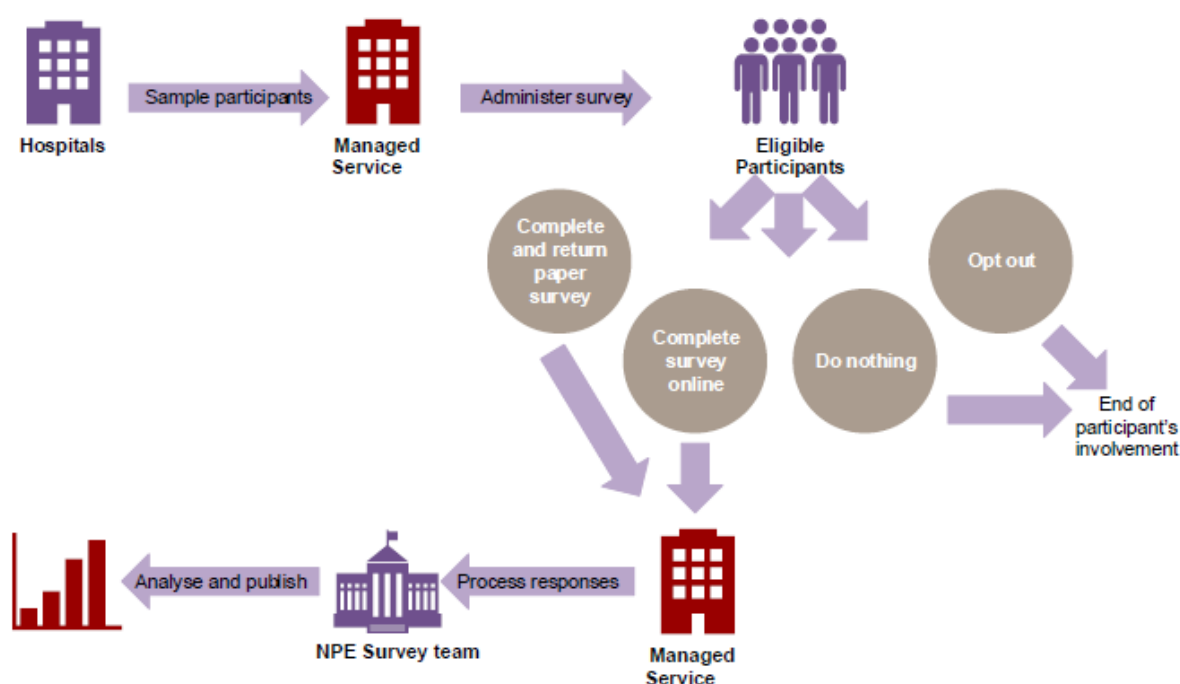
The survey programme's steering group favoured the adoption of a bi-modal (that is, paper with Freepost return, or online) response and single modal contact (that is, invitation via post) design for the following reasons:

1. Patients' email addresses are not routinely collected by hospitals and could thus not be used as a second mode of contact.
2. It was not feasible to contact participants via telephone as landline non-coverage is problematic and costs would be too high to implement this.
3. It was not feasible to contact participants via mobile phone given the size of the sample and the perceived invasiveness of recruiting participants in this manner.
4. It was decided to provide an online response option in order to 'future-proof' the survey.
5. It was decided to offer postal return as this is often the preferred and most successful response mode.<sup>(4)</sup>

Figure 1.1. below outlines the model and design of the National Patient Experience Survey. This model is closely aligned to that of the national inpatient survey in the United Kingdom.



**Figure 1.1. The National Patient Experience Survey process**



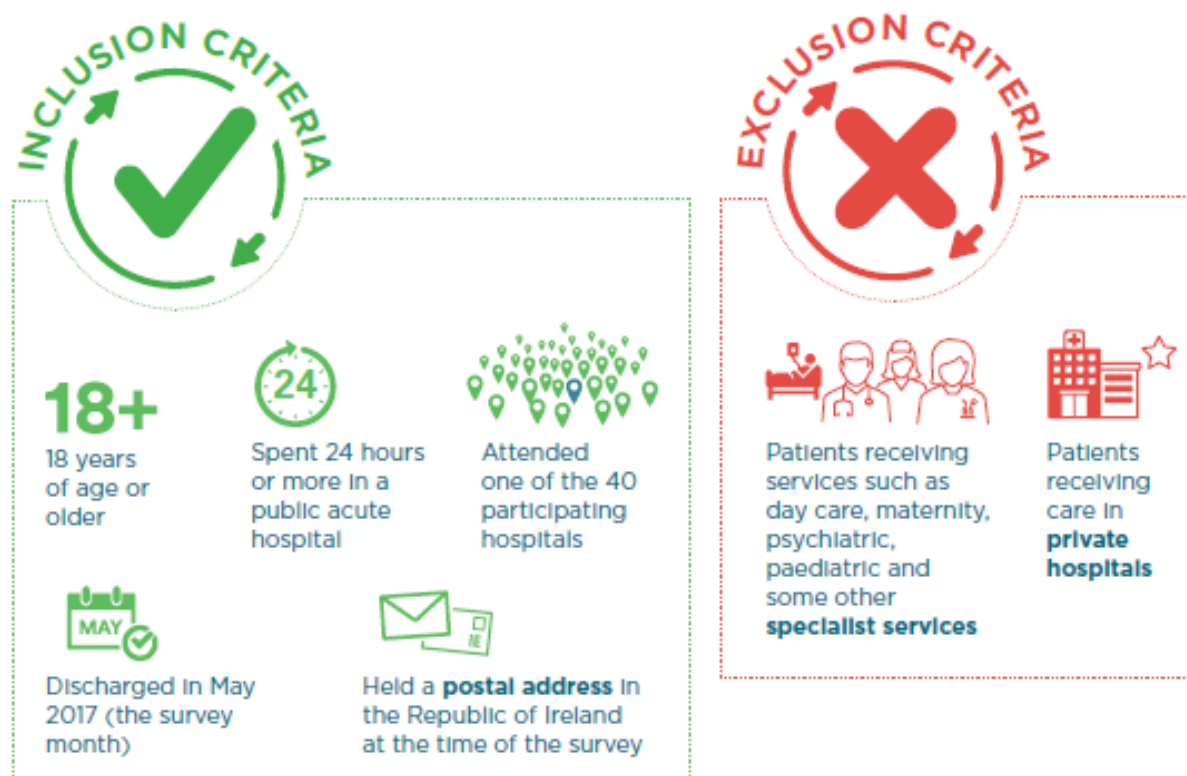
### 1.4.2. Sample

In total, 40 public acute hospitals, from six<sup>3</sup> of Ireland's seven hospital groups, participated in the National Patient Experience Survey in 2017. Private, maternity and paediatric hospitals did not participate in the survey.

The sample for the National Patient Experience Survey comprised all adult patients discharged during 1 May – 31 May 2017, who spent 24 hours or more in a public acute hospital and who held an address in the Republic of Ireland. Patients who received maternity, psychiatric, paediatric and other specialist services were not eligible to participate in the survey on this occasion. Figure 1.2. summarises the inclusion and exclusion criteria for the 2017 survey.

<sup>3</sup> The Children's Hospital Group is the seventh hospital group in Ireland.

**Figure 1.2. Included and excluded hospitals and patients**



## 1.5. Project schedule

The National Patient Experience Survey 2017 consisted of five major phases:

- exploratory and model design phase (including question selection and the development of the survey tool)
- testing
- implementation
- analysis
- reporting.

Each phase is described in detail in the chapters that follow.

## 2. Exploratory and model design phase

### Summary

#### Exploratory and model design phase (January 2015 – April 2017)

The exploratory and design phase to conduct a national survey of inpatient experience commenced in January 2015. During this phase, the following milestones were achieved:

- an international review of patient experience surveys was conducted<sup>(3)</sup>
- on the basis of the international review, a concept proposal was developed, for which ethical approval was granted
- a privacy impact assessment was conducted
- an information governance framework was developed for the survey programme
- a survey tool was developed to capture patient experience data
- stakeholder events were organised to engage with hospitals and to inform them about the survey programme
- a website and a communications plan were developed to support the promotion of the survey and the publication of results.

### 2.1. Ethical approval

Ethical approval provides an independent ethical review of the proposed research methodology under the following principles:

- respect for the person
- privacy and confidentiality
- validity of the study
- risks
- justice.

The National Patient Experience Survey team submitted an application to the Royal College of Physicians in Ireland (RCPI) Research Ethics Committee on behalf of the National Patient Experience Survey Programme. Ethical approval for the survey was obtained in January 2017.

## 2.2. Privacy Impact Assessment

Given the fact that the administration of the National Patient Experience Survey requires the processing of personally identifiable information (e.g. patient contact details, dates of birth, etc.), the National Patient Experience Survey Programme Steering Group commissioned a privacy impact assessment (PIA) in 2016. The PIA was conducted by an independent third party.

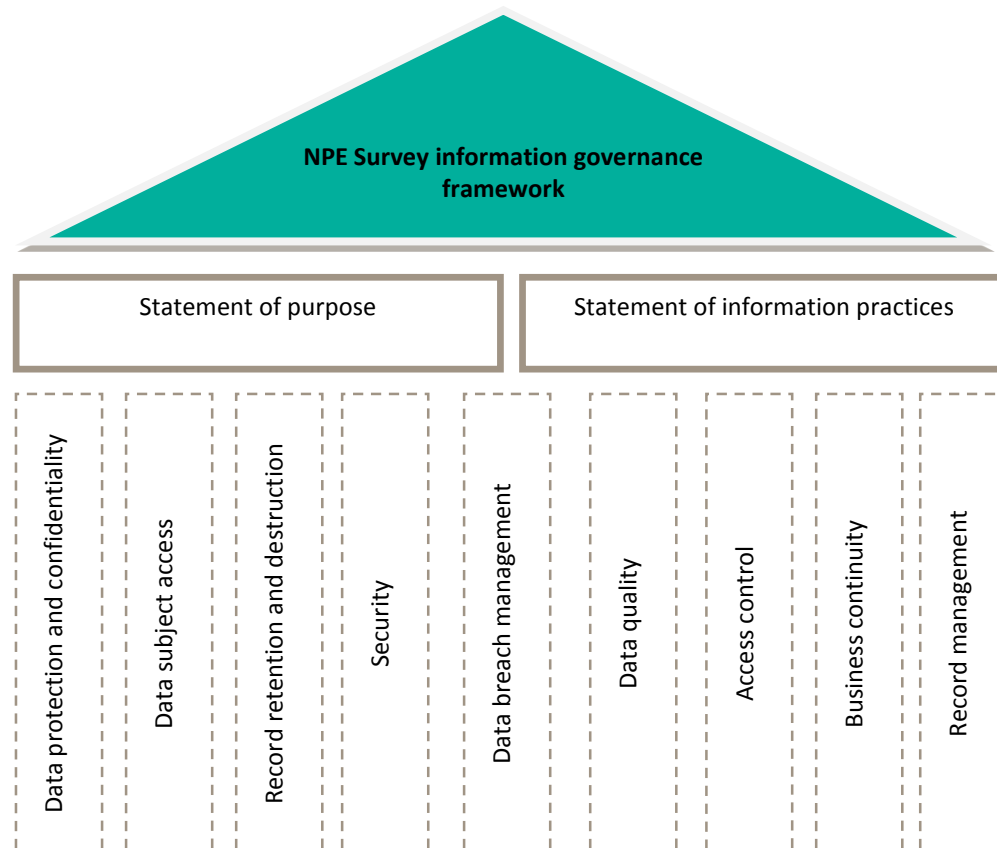
The PIA identified a total of ten privacy risks and suggested that controls be built into the survey design to minimise the privacy impacts on participants. The PIA was instrumental in identifying the security requirements of the National Patient Experience Survey Programme at the design stage. As such, privacy considerations and risk controls could be built into the design of the survey methodology. The summary PIA is available to download from [www.patientexperience.ie](http://www.patientexperience.ie).

## 2.3. Information governance

Information governance is a means of ensuring that all data, including personal information, is handled in line with all relevant legislation, guidance and evidence-based practices. The PIA required that all personally-identifiable information collected during the survey fieldwork was classified as sensitive and treated as such. On the basis of the recommendations of the PIA, the National Patient Experience Survey Programme developed a comprehensive information governance framework ensuring that any information it collected was handled safely and securely.

The National Patient Experience Survey Programme information governance framework comprises of policies, procedures and processes covering: data protection and confidentiality, data subject access requests, record retention and destruction, security, data breach management, data quality, access control, business continuity and record management. A statement of purpose and statement of information practices detailing the information handling practices of the National Patient Experience Survey are publically available on [www.patientexperience.ie](http://www.patientexperience.ie). Figure 2.1. below provides a schematic overview of the National Patient Experience Survey information governance framework.

**Figure 2.1. Schematic depiction of the National Patient Experience Survey information governance framework**



## 2.4. The National Patient Experience Survey questionnaire

### 2.4.1. Overview

The questionnaire for the National Patient Experience Survey was developed over several stages in 2016/2017. Various methods were employed seeking input from as many subject experts as possible, and patients in particular. Question selection and questionnaire development were carried out in five steps:

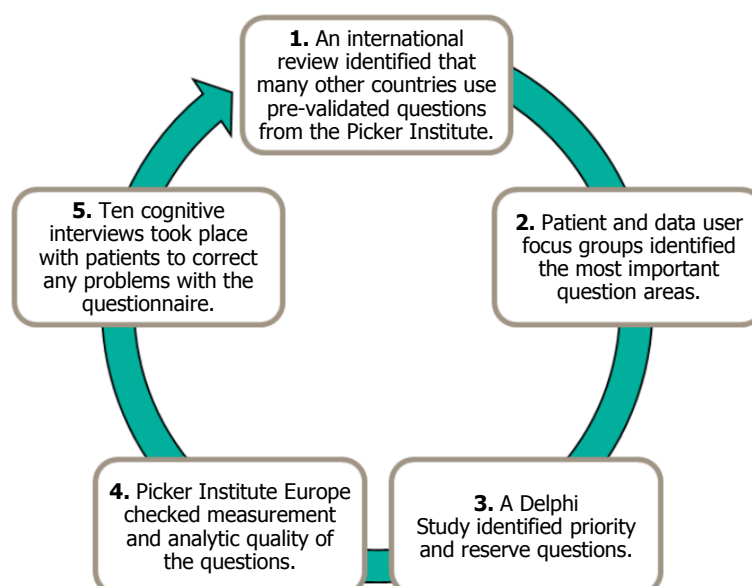
1. An international review of patient experience surveys<sup>(3)</sup> was conducted in 2016 and found that the majority of jurisdictions reviewed used questions developed by the Picker Institute. A library of 189 internationally-validated questions was subsequently purchased from the Picker Institute to use as a basis for the survey questionnaire in Ireland.
2. Eight focus groups<sup>(5)</sup> were conducted over a three-week period in May and June 2016. Six of the focus groups were conducted with patients from hospitals of the participating hospital groups. In addition, two data-user focus groups were conducted in Dublin and Cork. The purpose of the focus groups was to determine which questions would be relevant for the Irish context.

3. A two-round Delphi study<sup>(6)</sup> was commissioned to identify a priority set of 60 questions for inclusion in the survey. The study was designed to integrate the findings from the focus group discussions and to further refine the question set.
4. The Picker Institute Europe<sup>(7)</sup> reviewed the results of the study and recommended a small number of changes to improve overall measurement quality.
5. Cognitive interviews<sup>(8)</sup> were conducted with ten patients and patient representatives. The aim of the interviews was to identify any difficulties respondents may have answering questions, to identify and fix problems with layout, routing and flow of the questionnaire.

Each step of the questionnaire development for the National Patient Experience Survey has been documented and the various reports can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

The findings from the focus groups, the Delphi study, expert advice from Picker Institute Europe and the results from the cognitive interviews are reflected in the final survey questionnaire. Figure 3.2. summarises the questionnaire development process.

**Figure 2.2. Steps in the development of the National Patient Experience Survey tool**



The final survey questionnaire comprised of 61 questions, 58 of which were closed tick-box questions and three of which were open-ended questions to allow participants to comment on positive and negative aspects of their hospital care. The complete question set is included in Appendix 1. A sample copy of the final survey questionnaire can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

## 2.4.2. Mapping of survey questions to stages and aspects of care

For analytic and reporting purposes, questions were grouped into 'stages of care' and 'aspects of care'. These categorisations form distinct 'lenses' through which to view and understand patients' experiences in hospital. The mapping of the survey questions to themes was done prior to data collection to permit the development of an online reporting platform or survey dashboard (see Chapter 6). A data-driven approach could therefore not be used. Instead, four possible mappings were developed and reviewed by hospital group and hospital representatives, as well as representatives of each of the three partner organisations and the steering group for the survey programme. The four mappings corresponded to the *National Standards for Safer Better Healthcare* :<sup>(9)</sup> (theme 1: patient-centred care and support), the National Healthcare Charter pillars of care<sup>(10)</sup>, Picker-type principles of care (aspects of care) and the patient journey (stages of care).

This consultation indicated a preference for the last two mappings. 'Aspects of care' loosely correspond to the Picker principles of patient centred-care<sup>(11, 12)</sup>. 'Stages of care' correspond to the various phases of the patient's journey through hospital, from admission to discharge. The Picker Institute reviewed and validated the proposed question groupings in April 2017. Table 2.1. provides a brief description of stages and aspects of care.

**Table 2.1. Description of stages and aspects of care**

Stage of care (patient journey)	Aspect of care
<u>Admissions:</u> experiences in the emergency department such as communication with staff and privacy.	<u>Values, preferences and needs:</u> experiences relating to dignity and respect, patient involvement in care and treatment and privacy.
<u>Care on the ward:</u> experiences while on the ward such as communication with hospital staff, privacy, pain management, cleanliness and food.	<u>Physical comfort:</u> experiences relating to the hospital ward and environment, food, and assistance with eating and self-care.
<u>Examination/diagnosis/treatment:</u> experiences while undergoing or receiving the results of tests, treatments, operations and procedures.	<u>Informing/explaining:</u> experiences relating to the manner in which hospital staff communicate or explain information to patients.
<u>Discharge/transfer:</u> experiences relating to discharge such as notice of discharge, and provision of information, advice and support.	<u>Relating/supporting:</u> experiences relating to supporting patients and promoting good relationships between staff and patients.
	<u>Continuity and transition:</u>

experiences relating to the discharge process such as notice of discharge, and provision of information, advice and support.

Tables 2.2. and 2.3. specify the number of questions corresponding to the stages and aspects of care. Filter questions, that is, questions whose main purpose it was to route respondents to the next applicable question, were excluded from both categorisations. Six questions on respondent demographics and the three open-ended questions were also excluded.

The patient journey is organised into four distinct stages of care. Four questions asked about general aspects of hospital care and were thus included into a fifth category — 'other'. 14 survey questions asked questions about 'care on the ward' (28.6%), followed by questions on 'examination/diagnosis/treatment' (26.5%) and 'discharge and transfers' (24.5%).

**Table 2.2. Number of questions by stage of care (patient journey)**

Stage of care (patient journey)	Frequency	Percent
Admissions	5	10.2
Care on the ward	14	28.6
Examination/diagnosis/treatment	13	26.5
Discharge/transfer	12	24.5
Other	4	8.2
Overall	1	2.0
<b>Total</b>	<b>49</b>	<b>100.0</b>

The questionnaire was further divided into seven aspects of care. The survey included ten questions on 'informing/explaining', 'relating/supporting' and 'continuity/transition'. It asked a further eight questions on 'physical comfort' and nine questions on 'values, preferences and needs'. One question related to 'access to care' (i.e. emergency department waiting times) and 'overall experience' respectively.

**Table 2.3. Number of questions by aspect of care**

Aspect of care	Frequency	Percent
Access to care	1	2.0
Physical comfort	8	16.3
Values, preferences and needs	9	18.4
Informing/explaining	10	20.4
Relating/supporting	10	20.4
Continuity and transition	10	20.4
Overall	1	2.0
<b>Total</b>	<b>49</b>	<b>100.0</b>



The selection of survey questions and their subsequent allocation to themes was the result of the questionnaire development process, which sought to accommodate a multitude of preferences (from patients and subject matter experts), rather than seeking to achieve an even coverage of themes.

In the national report of the survey results<sup>(13)</sup>, findings were reported as 'stages of care' only. Appendix 2 shows how individual questions map to stages and aspects of care.

### **2.4.3. Development of an online version of the survey tool**

The online survey tool was developed during February - April 2017. The online version of the survey was designed for personal computers, laptops and mobile devices, compatible with the most widely-used internet browsers.

In an effort to limit mode effects, the online questionnaire was designed to mimic the paper questionnaire format as much as possible. Similar to the paper questionnaire, individual questions were sectioned off. They were also placed on a light grey background. The survey literature highlights that respondents are generally more likely to process questions one by one if visual items are separated from one another.<sup>(14)</sup>

During the survey fieldwork (1 May 2017 to 26 July), invited participants could take the survey online on [www.patientexperience.ie](http://www.patientexperience.ie). To start the survey, participants entered their eight-digit survey code, which was provided to them in the initial invitation and subsequent reminder letters. The survey code also featured on the bottom left-hand corner of the cover page of the paper questionnaire.

### **2.4.4. Development of the letters for survey participants**

At the point of discharge from hospital, eligible patients were handed an envelope containing an information letter and a patient information leaflet. The letter informed the patient that he or/she may be invited to participate in the National Patient Experience Survey (letter 1 in Appendix 3). Eligible participants received a survey pack in the post two weeks after their discharge from hospital. The survey pack contained an invitation letter (letter 2 in Appendix 3) and a copy of the questionnaire. The invitation letter explained why the recipient had received the survey, how to fill it in and how to opt-out if desired. It also listed contact details should a recipient wish to contact the National Patient Experience Survey Programme. The invitation letter had been tested as part of the cognitive interviews with patients and patient representatives.<sup>(8)</sup>

A first and second reminder letter were also designed (letters 3 and 4 in Appendix 3) and sent to eligible participants who had not yet completed the questionnaire or not yet opted-out of the survey. The reminders outlined the modes of survey completion and explained how to opt out of the survey. The second reminder letter was sent along with a second survey questionnaire. A template sympathy letter was drawn up (letter 5 in Appendix 3) to send to bereaved relatives of deceased participants who had received a survey pack in error. The letter was signed by the Director General of the HSE.

All letters drawn up for the National Patient Experience Survey are in plain English. The discharge, invitation and reminder letters seek to convey the importance of taking part in the survey and it is worth noting that both the letters and the questionnaire contained a prominent and direct appeal for help from the respondent: 'Please help us make hospital care better'. This suggestion came from the patient representatives who felt that a direct appeal might serve to engage respondents. The letters and the survey questionnaire were all translated into Irish; participants could request a copy by calling the information line.

## **2.5. Stakeholder engagement and communications**

### **2.5.1. Stakeholder engagement**

Given that the success of a national survey of inpatient experience depends entirely on the buy-in of hospitals and the correct application of sampling routines, it was decided to brief and engage with the participating hospitals well in advance of the survey fieldwork start date in May 2017. Multiple stakeholder events were organised in advance of the survey start to ensure that hospital management, communications and quality improvement personnel, as well as Patient Administration System (PAS)/IT staff understood their roles in implementing this important survey.

### **2.5.2. The National Patient Experience Survey website and communications plan**

The National Patient Experience Survey website ([www.patientexperience.ie](http://www.patientexperience.ie)) was a key communications and information resource during the survey period as well as the reporting phase, designed to target multiple audiences and to fulfil multiple functions. It was designed as an information repository for the general public, survey participants and hospital staff. Furthermore, participants could fill in or opt-out of the survey on the website, by logging in with their unique survey code. The national, hospital and hospital group reports, as well as the quality improvement plans, were published on the website in December 2017.

A communications plan was put in place to support the successful implementation of the National Patient Experience Survey 2017. In order to deliver on this plan, a communications group was formed consisting of representatives from HIQA, the HSE and the Department of Health. The group initiated a national media campaign which coincided with the start of the survey. Promotional resources were designed and delivered to the participating hospitals in advance of the survey start on 1 May 2017. The material delivered included specially-designed napkins, A4 and A3 laminated posters, patient information leaflets, table-top stands for restaurants and canteens, discharge information packs, and banner stands for receptions and waiting areas. Additional copies of the promotional resources could be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

An informational video was developed and hospitals could download this from the website to display on their digital screens throughout the survey month. Reminder posters were also designed, which were also available for download. Hospitals were encouraged to download, print and laminate reminder posters and to display them in outpatient clinics and other public places from 1 June 2017 onwards.

As part of a wider stakeholder engagement plan, the National Patient Experience Survey team presented at various conferences and events targeted at key stakeholders prior and during the survey period.

# 3. Testing phase

## Summary

### Testing phase (March 2017 – April 2017)

The hospital processes (extraction of eligible patients from hospital systems), administration of the survey online and by post, as well as data processing systems, related to the implementation of the survey were all tested. The email and telephone helpline routines for dealing with participant queries about the survey were also tested. Following the conclusion of the testing phase, final amendments were made to sampling processes, the online survey tool and helpline scripts.

### 3.1. Aims of the testing phase

The testing phase took place throughout March and April 2017. During this phase, all processes associated with the implementation of the survey were assessed.

The overall aim of the testing phase was to ascertain the readiness of the participating hospitals and the managed service for the implementation of the survey. The testing phase allowed the hospitals, the managed service and the National Patient Experience Survey team to identify concerns or issues and to solve these in time for the start of the survey.

### 3.2. Data extraction of patient information

Data extraction of patient information refers to the sampling procedures undertaken during the survey fieldwork. Hospitals participating in the 2017 survey were required to extract personal data (such as name and address) of eligible patients at specific intervals during a specific timeframe. The data extracted was subsequently shared with the managed service, which was responsible for distributing invitation letters and survey questionnaires to eligible participants. PAS and IT staff were responsible for the data extraction in each participating hospital.

The data extraction and quality assurance processes required for the successful administration of the survey were documented in a guidance manual, distributed to hospitals well in advance of the testing phase. The guidance manual can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie). Personnel responsible for data extraction and quality assurance of extracts were advised to follow this guidance during every step of the process outlined to ensure a standardised and consistent approach to the implementation of the survey across all participating hospitals.

### **3.3. Testing data extraction of patient information**

Testing the identification of eligible participants and the extraction of their information for the purpose of administering the survey was a key component of the testing phase. This particular aspect of the testing phase took place from 16 to 24 March 2017. The testing phase also involved the testing of the correct application of quality assurance procedures and the removal of deceased patients from the sampling records. It also presented an opportunity to for PAS/IT staff to familiarise themselves with the sampling inclusion and exclusion criteria as well as relevant HSE security policies.

The testing phase confirmed that the data extraction processes, if followed correctly, result in high-quality data. A number of minor adjustments were made to the sub-processes prior to the commencement of the survey in line with the results of the testing phase.

### **3.4. Testing of the survey tool**

The administration of the final survey was also assessed during the testing phase. This included testing the administration of both the paper and online versions of the survey. Survey packs were sent out, via postal service, to 30 users who tested the survey. Test users could complete the survey either online or return the questionnaire by Freepost. Feedback about the paper and online questionnaire was generally very positive. Nonetheless, users identified technical bugs in the online survey and suggested additional design and navigation improvements, all of which were implemented in advance of the survey start in May 2017.

### **3.5. Testing of the National Patient Experience Survey information line and email**

The Freephone and email helplines were also tested as part of this process. Both contact points were set up to deal with public queries related to the National Patient Experience Survey. Participants could call the helpline or email [info@patientexperience.ie](mailto:info@patientexperience.ie) if they wished to opt-out of the survey, or if they required assistance (over the phone) with filling in the survey. Test users were assigned a scenario which they were asked to recount by calling the helpline or writing an email to [info@patientexperience.ie](mailto:info@patientexperience.ie). Examples of scenarios included requests to opt-out of the survey, queries on locating survey codes, complaints by bereaved family members whose deceased relatives mistakenly received a survey questionnaire and queries around data protection. Test users were asked to provide written feedback on how adequately their queries were dealt with by the helpline and email support teams.

Positive feedback was received about the overall tone and the supportive and

professional manner of all the helpline staff. Following the test phase, minor revisions were made to the helpline and email scripts. Procedures to quickly handle email queries requiring sensitivity, which were not covered in existing templates, were also developed.

# 4. Implementation phase

## Summary

### Implementation phase (May 2017 – July 2017)

While the eligibility period for the survey ended on 31 May 2017, the survey fieldwork continued for an additional two months until 26 July 2017. After this date, online completion of the survey was no longer possible and surveys returned by paper were no longer processed. 26,635 people were invited to participate in the 2017 survey, with 51% returning a valid survey questionnaire. The vast majority of participants returned a paper questionnaire, with 10% of people filling in a survey online.

### 4.1. Aims of the implementation phase

The aims of the implementation phase were to successfully deliver the National Patient Experience Survey. This involved distributing the questionnaire to sampled patients, record response status and follow up with reminder letters, to monitor response rates, and to monitor activity on the Freephone information line and support email.

### 4.2. The survey fieldwork

The survey fieldwork spanned the period of 1 May – 26 July 2017. Survey invitations and questionnaires were sent to participants two weeks after their discharge. The length of the survey cycle is typically determined by the number of additional reminders sent to participants after they leave hospital. For the 2017 survey cycle, two additional reminders were sent out. Reminder letters and questionnaires were sent at two fortnightly intervals to eligible individuals who had not yet returned a survey. The last batch of reminder letters was sent out on 12 July 2017. Participants could return their questionnaires until 26 July 2017. Surveys received after this date were not processed and were discounted from the analysis.

Data extraction and delivery of patient information from the hospitals to the managed service for the purposes of sending invitations to potential participants

commenced on 10 May 2017. The final data extraction took place on 8 June 2017. The following patient information was collected: the patient's name, address, date of birth, gender, date of admission, source of admission, date of discharge, discharge destination, length of stay, provider hospital group and hospital name details.<sup>4</sup> During the month of May 2017, participating hospitals performed a total of five extractions of patient information and exchanged this information with the managed service. Data extracts for each reference week (1-5) were sent to the managed service on the dates outlined in Table 4.1.

**Table 4.1. Schedule for data extraction**

<b>Extract coverage</b>	<b>Agreed date of receipt (close of business on each date)</b>
Week 1 (1 – 7 May)	Wednesday, 10 May 2017
Week 2 (8 – 14 May)	Wednesday, 17 May 2017
Week 3 (15 – 21 May)	Wednesday, 24 May 2017
Week 4 (22 – 28 May)	Wednesday, 31 May 2017
Week 5 (29 – 31 May)	Thursday, 8 June 2017

Data transfers to the managed service occurred through a secure transfer mechanism to ensure the safety of patient-identifiable information while in transfer. Upon receipt of the data files, patient details were uploaded to a master file. A review of death notifications was carried out weekly by every participating hospital and the names of patients who had passed away since their discharge from hospital were transferred to the managed service in a separate file using the same secure transfer specifications. The managed service subsequently removed those names from the master file.

### **4.3. Sampling and operational outcomes**

A total of 27,077 people were eligible to participate in the National Patient Experience Survey 2017. 442 individuals passed away during the survey period of 1 May -26 July 2017, while 556 individuals actively opted out of the survey. A total of 21,781 first reminders, and 17,150 second reminders were sent out during the survey period. Table 4.2. details sampling and operational outcomes on a weekly basis for the entire survey period.

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<sup>4</sup> The transfer participant data, between hospitals (data controllers) and the managed service (data processor on behalf of HIQA) was in all instances mandated by data sharing agreements.



**Table 4.2. Weekly numbers of persons sampled, first invitations, first reminders, second reminders, deaths, opt-outs, paper completions, and online completions**

	<b>Total persons sampled</b>	<b>Weekly N of first invitations sent</b>	<b>Weekly N of first reminders sent</b>	<b>Weekly N of second reminders sent</b>	<b>Weekly N of deaths logged</b>	<b>Weekly N of opt-outs logged</b>	<b>Weekly N of paper completions</b>	<b>Weekly N of online completions</b>
Week 1 (as at 19 May)	11965	6246	0	0	0	0	13	11
Week 2 (26 May)	18008	6042	0	0	26	69	762	101
Week 3 (2 June)	24159	6151	4715	0	40	42	1575	136
Week 4 (9 June)	27077	2918	4696	0	56	91	1745	106
Week 5 (16 June)	27077	0	4705	3380	57	98	1587	166
Week 6 (23 June)	27077	0	5286	4114	66	38	2259	152
Week 7 (30 June)	27077	0	2379	3824	46	113	1371	224
Week 8 (7 July)	27077	0	0	4009	53	29	1543	139
Week 9 (14 July)	27077	0	0	1823	86	21	874	62
Week 10 (21 July)	27077	0	0	0	4	39	614	29
Week 11 (26 July, survey close)	27077	0	0	0	8	16	211	26

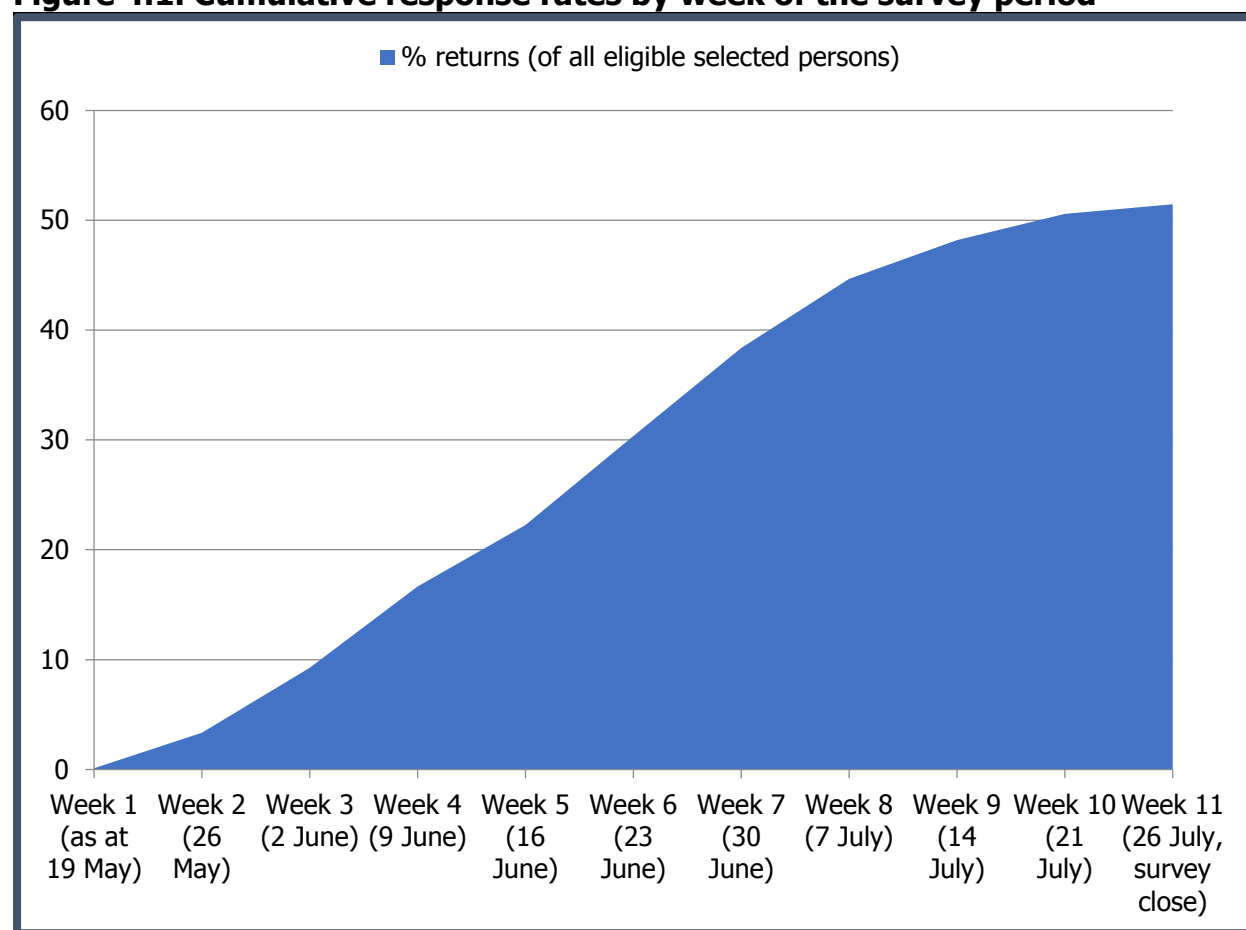
## 4.4. Response rates

Surveys returned before or on 26 July 2017, which contained a response to at least one question, were considered valid. Blank questionnaires, returned within the same timeframe, were considered opt-outs. Individuals who returned a blank questionnaire were removed from the master file and did not receive any further reminder letters. Of the 26,635 people who were ultimately eligible and invited to participate, 13,706 people returned a valid survey questionnaire prior to the survey closing date on 26 July 2017, resulting in a national response rate of 51% (Table 4.3.). 12,554 individuals completed the survey on paper and sent it back by Freepost. Only about 10% (1,152) of surveys were filled in online (Table 4.2.).

Response rates were calculated by dividing the number of valid surveys received by the number of initial invitations sent, minus the number of people who passed away during the survey month. Figure 4.1. shows the cumulative response rates by week

during the survey period (1 May – 26 July 2017). 4,114 surveys were returned during week 6, this was the highest number returned during any week.

**Figure 4.1. Cumulative response rates by week of the survey period**



Response rates at the hospital group level were generally above 50%, with the exception of the RCSI Group, which had a response rate of 47.9%. The South/South West Hospital Group recorded the highest response rate at 54.5%. Table 4.3. shows the number of people invited to take part and the number taking part, as well as the corresponding response rate for each hospital group.

**Table 4.3. Number of people invited to participate, response numbers and response rate by hospital group**

Group	Number invited to take part	Number taking part	Response rate (%)
<b>National (Total)</b>	26,635	13,706	51.5%
<b>By Hospital Group</b>			
South/South West Hospital Group	5144	2804	54.5%
Ireland East Hospital Group	5661	2937	51.9%
RCSI Hospital Group	4248	2033	47.9%
UL Hospital Group	2036	1074	52.8%
Saolta Hospital Group	4649	2412	51.9%
Dublin Midlands Hospital Group	4897	2446	49.9%

*Source: The National Patient Experience Survey: findings of the 2017 inpatient survey*

As shown below, in Table 4.4., the response rates for eligible male patients (51%) and eligible female patients (52%) were broadly similar. People aged 66-80 years had the highest response rate (60%) of any age group. People aged 35 or younger were least likely to respond to the survey, with only 32% of those invited returning a valid survey questionnaire. Patients who stayed in hospital between three and five days were most likely to return a survey compared with patients who had shorter or longer stays. People who were admitted to hospital as a result of an emergency were less likely to respond to the survey, compared with people whose stay had been planned in advance.

**Table 4.4. Response and non-response composition for the National Patient Experience Survey 2017**

Group	Total discharged	Deceased	Opted out	No response	Completed (paper)	Completed (online)	Response rate (%)
All respondents	27077	442	556	12372	12554	1152	51%
<b>Sex</b>							
Males	13579	226	283	6312	6134	623	51%
Females	13498	216	273	6060	6420	529	52%
<b>Age group</b>							
18-35	3181	2	37	2129	800	210	32%
36-50	4204	23	38	2279	1561	303	45%
51-65	6069	60	85	2512	3093	319	57%
66-80	8403	178	202	3096	4693	236	60%
81 years or older	5220	179	194	2356	2407	84	49%
<b>Length of stay</b>							
Length of stay 1-2 days	9166	50	153	4274	4204	485	51%
Length of stay 3-5 days	7248	78	136	3111	3613	309	55%
Length of stay 6-10 days	5552	115	140	2406	2679	212	53%
Length of stay 11 or more days	5111	199	127	2581	2058	146	45%
<b>Admission route</b>							
Elective	3749	26	59	1359	2091	214	62%
Emergency	16463	315	361	7972	7155	658	48%
Other	6865	101	136	3041	3308	280	53%
Total	27077	442	556	12372	12554	1152	

Source: The National Patient Experience Survey: findings of the 2017 inpatient survey

Appendix 4 includes a detailed breakdown of operational outcomes and response rates by hospital group and individual hospital.

## 4.5. Survey information line and email outcomes

During the survey period 1 May – 26 July 2017, 1,101 calls were recorded by helpline operators, of which 270 (25%) occurred during week 8 (26 June – 02 July 2017). Table 4.5. shows the number of calls received weekly during the survey period.

**Table 4.5. Number of calls received by the Freephone line during the survey period**

Week	Calls	%	Week period	
Week 1	5	0%	08 May 2017	14 May 2017
Week 2	20	2%	15 May 2017	21 May 2017
Week 3	40	4%	22 May 2017	28 May 2017
Week 4	20	2%	29 May 2017	04 June 2017
Week 5	148	13%	05 June 2017	11 June 2017
Week 6	143	13%	12 June 2017	18 June 2017
Week 7	158	14%	19 June 2017	25 June 2017
Week 8	270	25%	26 June 2017	02 July 2017
Week 9	126	11%	03 July 2017	09 July 2017
Week 10	111	10%	10 July 2017	16 July 2017
Week 11	50	5%	17 July 2017	23 July 2017
Week 12	10	1%	24 July 2017	26 July 2017
<b>Grand total</b>	<b>1101</b>	<b>100%</b>	-	-

355 queries (32%) received during the survey period related to the fact that callers were sent a reminder letter even though they already completed the survey. 218 queries (20%) asked how to opt-out of the survey. Table 4.6. details the most frequent query types received and logged by operators of Freephone information line.

**Table 4.6. Summary of query types received by the Freephone information line**

Query type	Calls	%
This is the second letter I've gotten and I've already done the survey.	355	32%
Opt-out	218	20%
Unable to participate due to illness/relative or friend wants to participate instead	149	14%
General query about the survey — why are you writing to me? Who is conducting the survey? Can I see the results?	81	7%
Patient has passed away	80	7%
Lost questionnaire/resend me the survey	75	7%
Received my letter/survey pack but there is no questionnaire. What do I do?	61	6%
Haven't received a letter/Heard about survey. Can I participate?	60	5%
Received my letter/survey pack but there is no Freepost envelope. What do I do?	26	2%
Hospital staff query	10	1%

A total of 75 bereavement letters were sent to patients' families during the survey period. Bereavement letters were sent in the event that invitation or reminder letters were erroneously sent to individuals who had passed away following discharge from hospital.

Where callers provided a reason for opting out of the survey, 61% explained that they were having difficulties with reading or completing the survey due to, for example, sight difficulties. Table 4.7. outlines the most recurrent reasons for opt-out during the National Patient Experience Survey 2017.

**Table 4.7. Most frequent reasons for opt-out**

Reason for opt-out where given	
I have difficulty reading or completing the survey (for example, because of sight difficulties, illness)	61%
I don't have time	13%
I never take part in surveys of any kind	9%
I only have bad things to say/don't want to express them or take part	3%
My feedback is not suited to a survey	3%
I feel it is not going to make a difference	4%

Privacy issue/uncomfortable with needing assistance to complete	4%
Length or difficulty of survey	3%
Other	3%

# 5. Data processing and analysis phase

## Summary

### Data processing and analysis phase (May 2017 – August 2017)

The analysis and reporting phase began in early May 2017. During this phase the data from completed paper and online surveys was processed and uploaded onto a back-end data base. Data weighting/standardisation and scoring procedures were developed and agreed during this phase. A coding framework for the qualitative comments was also developed.

### 5.1. Aims of data processing and analysis

The aims of the data processing and analysis phase were to:

- ensure timely, quality-assured processing of the survey response data, in line with the survey programme's information governance framework, and
- allow selection and implementation of data analysis methodologies that are in accordance with international best practices.

All data processing was completed by late August 2017.

### 5.2. Data processing steps

Surveys were received both online and on paper, and paper-based responses were uploaded and merged with the online surveys as described below. The file structure follows the questionnaire design. All questions have single code responses. Table 5.1. outlines the file structure for the National Patient Experience Survey.



**Table 5.1. File structure of the survey responses 2017**

Q number	Valid codes	Q number	Valid codes	Q number	Valid codes
Q1.	<b>1,2,3</b>	Q22.	<b>1,2,3,4</b>	Q43.	<b>1,2</b>
Q2.	<b>1,2</b>	Q23.	<b>1,2,3,4</b>	Q44.	<b>1,2</b>
Q3.	<b>1,2,3,4</b>	Q24.	<b>1,2,3</b>	Q45.	<b>1,2,3,4,5</b>
Q4.	<b>1,2,3,4</b>	Q25.	<b>1,2,3</b>	Q46.	<b>1,2,3,4</b>
Q5.	<b>1,2,3,4</b>	Q26.	<b>1,2,3</b>	Q47.	<b>1,2,3,4</b>
Q6.	<b>1,2,3</b>	Q27.	<b>1,2,3,4,5,6</b>	Q48.	<b>1,2,3,4,5</b>
Q7.	<b>1,2</b>	Q28.	<b>1,2,3,4</b>	Q49.	<b>1,2,3,4,5</b>
Q8.	<b>1,2,3,4,5,6,7</b>	Q29.	<b>1,2,3</b>	Q50.	<b>1,2,3</b>
Q9.	<b>1,2,3</b>	Q30.	<b>1,2,3</b>	Q51.	<b>1,2,3,4</b>
Q10.	<b>1,2,3,4</b>	Q31.	<b>1,2,3</b>	Q52.	<b>1,2,3</b>
Q11.	<b>1,2,3,4,5</b>	Q32.	<b>1,2,3,4</b>	Q53.	<b>0-10</b>
Q12.	<b>1,2,3,4</b>	Q33.	<b>1,2,3,4,5,6,7</b>	Q54.	<b>1,2,3,4</b>
Q13.	<b>1,2,3,4</b>	Q34.	<b>1,2,3,4,5</b>	Q55.	<b>1,2</b>
Q14.	<b>1,2,3,4</b>	Q35.	<b>1,2,3,4</b>	Q56.	<b>YYYYMMDD</b>
Q15.	<b>1,2,3,4,5</b>	Q36.	<b>1,2,3,4,5</b>	Q57.	<b>1,2,3,4,5,6,7,8</b>
Q16.	<b>1,2,3</b>	Q37.	<b>1,2,3,4</b>	Q58.	<b>1,2,3,4</b>
Q17.	<b>1,2,3</b>	Q38.	<b>1,2,3</b>	Q59.	<b>OPENENDED</b>
Q18.	<b>1,2,3,4,5,6</b>	Q39.	<b>1,2,3</b>	Q60.	<b>OPENENDED</b>
Q19.	<b>1,2,3,4</b>	Q40.	<b>1,2,3,4</b>	Q61.	<b>OPENENDED</b>
Q20.	<b>1,2,3,4</b>	Q41.	<b>1,2,3</b>		
Q21.	<b>1,2,3</b>	Q42.	<b>1,2,3,4,5</b>		

### 5.2.1. Paper-based survey data

The processing of paper questionnaires began on 22 May 2017 and was completed by 1 August 2017. All completed questionnaires were returned to the managed service, where they were opened, date stamped, punched and coded. Data were captured into a customised data entry form developed in Askia software. The form was designed to quality assure the data upon entry. For example, data entry staff could not progress to the next field if an incorrect survey code (ID) was entered. Similarly, out-of range values were not permitted for any of the numeric fields.

### 5.2.2. Online survey data

The National Patient Experience Survey website allowed patients to input their eight-digit short code and complete the survey. Similar to the paper-based survey, invalid survey codes (IDs) were not permitted on login (an error message appeared asking the user to enter their code again), and the routing in the questionnaire was programmed into the online survey design.

### 5.2.3. Coding of survey data

To prepare the data for analysis and reporting, scoring (refer to section 5.3.2) and a number of post-entry recodes were applied to the survey response file (using SPSS 24).

Demographic variables were also produced at this stage:

- age of respondents was taken as 2017 minus the year of birth where month of birth was January to June, otherwise it was taken as 2017 minus the year of birth minus 1. Age was then collapsed into five categories of age groups (18 to 35, 36 to 50, 51 to 65, 66 to 80, 81 or older).
- ethnic group was collapsed into 'White, Irish' and 'Other'<sup>5</sup>.
- admission type was coded as 'Emergency' if the respondent had a code 1 to either Q1 (Was your most recent hospital stay planned in advance or an emergency? – Emergency or urgent) or Q2 (When you arrived at hospital, did you go to the Emergency Department? – Yes) or if they answered one or more of Q3-Q6. Otherwise, it was coded as 'non-emergency'.

The question on overall experience (Q53, rated 0-10) was collapsed into three groups: very good (9-10), good (7-8), and fair to poor (0-6).

#### **5.2.4. Destruction of administrative data**

Patients' contact details were used to distribute the questionnaire to participants' home addresses. Information on date of birth, gender and other relevant variables was collected in order to describe the characteristics of the sample. Patients' names and addresses (with the exception of 'county name') were deleted at the close of the survey period. Paper, hard copies of the survey questionnaire were destroyed once all answers had been coded and correctly uploaded to the response file. Data access requests from participants were accommodated until 31 July 2017.

### **5.3. Quantitative methodology**

This section describes the methods adopted to calculate and apply the weights used to adjust for demographic variations across hospitals and hospital groups. This section also explains how the theme scores were calculated, outlines the criteria used to report results (reporting caveats), and describes the quality assurance of the numeric survey data.

#### **5.3.1. Demographic adjustment weights**

The results of the survey are based on standardised data, using a process that seeks

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<sup>5</sup>It must be acknowledged that this 'other' group contains a range of ethnicities, but binary coding was used in this instance due to the low percentage overall classed as 'Other'.

to minimise potential bias in responses. Previous patient experience surveys have demonstrated that a respondent's characteristics, such as their age and type of admission (e.g. emergency or elective) can influence survey responses.<sup>(15)</sup> Older respondents, for example, tend to report more positive experiences than younger respondents, while those admitted to hospital on an emergency basis report more negative experiences than those admitted on a non-emergency basis.<sup>(16)</sup> As there is considerable variation in the age and admission profile of patients across hospitals, there is potential for bias, with hospitals appearing better or worse than if they catered for patients with a different demographic profile. In order to address this issue and facilitate 'like for like' comparisons, the data was standardised. Standardising adjusts for the differences in respondent profiles in order to allow for fairer comparisons than could be made with non-standardised data.

In the analysis for the National Patient Experience Survey 2017, responses were standardised by age and type of admission. This approach was taken based on analysis of responses and guidance from the Picker Institute Europe which indicated that age and type of admission were the most significant sources of potential bias.

The standardisation process involves applying a 'weight' to each respondent within a particular hospital, which adjusts the value of their responses in proportion to the profile of the national sample of respondents. The first step in developing weightings is to calculate the proportion of the national sample of respondents in each age/admission group. Table 5.2. shows the proportion of respondents within each age group, categorised by type of admission. For example, the proportion of the national sample aged 18-35 who had an emergency admission was 0.057; the proportion of the national sample aged 51-65 who had a non-emergency admission was 0.092 etc. These proportions were then calculated for each hospital using the same procedure.

**Table 5.2. National proportions**

Admission type	Age	Hospital A
Emergency	18-35	0.049
	36-50	0.094
	51-65	0.159
	66-80	0.194
	81+	0.114
Non-emergency	18-35	0.036
	36-50	0.061
	51-65	0.146
	66-80	0.120
	81+	0.028

The next step was to calculate the weighting for each individual. Age/admission type weightings for individuals were calculated for each respondent by dividing the national proportion of respondents in their age/admission type group by the

corresponding hospital proportion.

This process identifies respondents within hospitals from groups that are over- or under-represented compared to the national profile of respondents. For example, if a lower proportion of people admitted as emergency patients and aged between 66 and 80 within Hospital A responded to the survey, in comparison with the national proportion, then this group would be under-represented in the final scores. Dividing the national proportion by the hospital proportion results in a weighting greater than “1” (1.319) for members of this group (Table 5.3.). This increases the influence of responses made by respondents within that group in the final score, thus counteracting their low representation.

**Table 5.3. Proportion and weighting for Hospital A**

Admission type	Age	National proportion	Hospital A proportion	Hospital A weight (national/hospital A)
Emergency	18-35	0.057	0.049	1.175
	36-50	0.094	0.094	1.004
	51-65	0.174	0.159	1.091
	66-80	0.256	0.194	1.319
	81+	0.132	0.114	1.154
Non-emergency	18-35	0.020	0.036	0.550
	36-50	0.045	0.061	0.742
	51-65	0.092	0.146	0.632
	66-80	0.102	0.120	0.853
	81+	0.027	0.028	0.974

Likewise, if a considerably higher proportion of people admitted as non-emergency patients aged between 36 and 50 years from Hospital A responded to the survey, then this group would be over-represented within the sample, compared with the national representation of this group. Subsequently this group would have a greater influence over the final score. In order to counteract this, dividing the national proportion by the proportion for Hospital A results in a weighting of less than one (0.742) for this group.

To prevent the possibility of excessive weight being given to respondents in an extremely underrepresented group, the maximum value for any weight was set at five, in line with the approach taken in the UK.<sup>(17)</sup>

### 5.3.2. Stage of care scores

To calculate scores for the themes described in Chapter 3, the responses to the questions making up these stages of care were assigned a score, using methods equivalent to those used in the UK by the Care Quality Commission (CQC).<sup>(18)</sup> The

scores applied to each of these questions are shown in Appendix 2. Table 6.4. shows an example of the original and scored data for the admissions stage of care. A stage of care score was generated for each respondent with one or more 'scorable' responses on that item making up that theme. Scores ranged from 0 to 10, with higher scores indicating a better experience. Refer to Appendix 2 for the wording and response options for the questions shown in Table 5.4.

**Table 5.4. Example scored responses for the 'Admissions' stage**

Original responses					Scored responses					Admissions stage score
Q3	Q4	Q5	Q6	Q8	RQ3	RQ4	RQ5	RQ6	RQ8	
1	1				10	10				10
1	2	2	2	2	10	5	5	5	7.5	6.5
1	1	3	3		10	10	0	0		5
2	2	4		6	5	5				5
4	4	4		6						[Missing]

### 5.3.3. Comparisons of groups

Statistical tests were carried out to examine if there were significant differences in patient experience across groups of patients and hospital groups. In the national report, men and women, different age groups and hospital groups were compared to one another. In the hospital group reports, average stage of care scores for hospitals were compared to the national averages. In the hospital group reports, individual hospitals belonging to a group were compared with the group average.

A 'z-test' was used to compare patient experience data at the 99% confidence level. A z-test is a statistical test used to examine whether two population mean scores are different when the variances are known and the sample size is large. A statistically significant difference means it is very unlikely that results were obtained by chance alone if there was no real difference. Therefore, when a score is 'higher than' or 'lower than' the national average, this is highly unlikely to have occurred by chance.

### 5.3.4. Reporting caveats

To protect the anonymity of respondents and to maintain an acceptable level of reliability of data at the hospital level, the individual hospital results for those with fewer than 30 respondents were not published.<sup>6</sup> All of the participating hospitals exceeded the 30 respondent thresholds. It should be noted, however, that it had been decided to merge the data for Louth County Hospital, Dundalk with Our Lady of Lourdes Hospital, Drogheda. The former had only 39 eligible discharges in May,

<sup>6</sup> This is the same criterion as used in the UK.

2017, and is a partner facility of the latter.

The second caveat relates to representativeness, whereby a hospital or hospital group with less than a 25% response rate would be flagged in reporting, with caution advised in interpreting the results. Again, however, this was not necessary, since all hospitals and hospital groups exceeded the 25% response rate (see Appendix 4).

### **5.3.5. Quality assurance of quantitative data**

Prior to uploading the data extract for each reference week, PAS staff implemented a number of quality-assurance checks. Similarly, following receipt of the data extract files, the managed service performed additional checks to ensure that any duplicates were removed and that the extracts did not contain any missing or implausible values.

Quality assurance was built insofar as possible into the design of the data capture for the paper-based survey responses. Thorough checking of the online data capture and cross-checks between the online and paper survey response data during the testing phase confirmed that the data were accurately captured, merged and uploaded to the online platform. In addition, the managed service undertook to double enter<sup>7</sup> 3% of all paper-based surveys received. Comparisons of the first and second entries confirmed the very high quality of the data entry, with only 0.0003% of verified questionnaires requiring revision.

Frequency checks on the merged (paper-based and online) survey data also confirmed that the rate of 'missingness' on the individual survey questions was in the low range; that is, there was no substantial evidence of 'survey fatigue' whereby rates of missing responses would be higher for questions appearing later in the questionnaire. For example, missing responses averaged 3.6% for Q9-Q11 compared with 5.6% for the last 3 numeric (closed response) questions prior to the demographic section (Q49-Q51). The average rate of missingness for the demographic questions (Q54-Q58) was 1.8%.

## **5.4. Qualitative methodologies**

This section describes the processing of the qualitative data collected in the survey questionnaire; that is, responses to the last three (open-ended) questions:

- Q59 – Was there anything particularly good about your hospital care?

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<sup>7</sup> A random selection of paper-based questionnaires were coded a second time and compared with the original codes in order to assess coding accuracy.

- Q60 – Was there anything that could be improved?
- Q61 – Any other comments or suggestions?

First, the number of responses received is reviewed. Then, the anonymisation procedure and the coding of the responses into themes for reporting is described.

#### 5.4.1. Numbers of qualitative responses received

Table 5.5. shows the number of responses received for each question by age group, sex, admission route and response mode (paper or online). The comment response rates appear to be in line with the overall response rates. This would suggest that there was no major over- or under-representation.

**Table 5.5. Number of responses received to Q59, Q60 and Q61 overall and by sex, age group, admission route, and response mode**

Group	Q59		Q60		Q61	
	N responses	% of respondents	N responses	% of respondents	N responses	% of respondents
All respondents	8,975		7,243		4,758	
Males	4,322	48.2	2,951	45.7	2,171	45.6
Females	4,653	51.8	3,512	54.3	2,587	54.4
Age 18 to 35	693	7.7	644	10	406	8.5
Age 36 to 50	1,301	14.5	1,090	16.9	800	16.8
Age 51 to 65	2,487	27.7	1,793	27.7	1,348	28.3
Age 66 to 80	3,162	35.2	2,043	31.6	1,510	31.7
Age 81 or older	1,332	14.8	893	13.8	694	14.6
Emergency	6,422	71.6	4,828	74.7	3,511	73.8
Non-emergency	2,553	28.4	1,653	25.3	1,247	26.2
Paper	8,145	90.8	5,723	88.6	4,260	89.5
Online	830	9.2	740	11.4	498	10.5

#### 5.4.2. Anonymisation of qualitative data

All qualitative responses were anonymised. Whether on paper or online, the same set of procedures was followed. The overarching principle guiding these procedures was the protection of the anonymity of individuals, whether respondents or hospital staff.

Training for anonymisation procedures was conducted in May 2017. The redaction guidelines can be found in Appendix 5.

### 5.4.3. Developing thematic codes for the qualitative data

As soon as sufficient data had been received, a coding framework was developed for the three open-ended questions, that is Q59-Q61.

It was agreed that:

- a pre-existing frame should not be forced onto the data (i.e. the frame should be data-driven)
- it should be possible to apply the same frame across all three questions, and
- a single response could contain multiple themes.

A coding framework was developed and tested on a sample of approximately 200 responses. This framework consisted of 23 codes initially.

The fitness for purpose of the draft coding frame was reviewed on the basis that the sample coding and additional observations on the data had been submitted as the implementation stage advanced. A review confirmed that the frame was largely fit for purpose, but that additional codes were required for the following:

- comments relating to health insurance
- comments relating to the handling of information regarding clinical details, medical history or medication
- Q61 only (any other comments?) which would categorise the responses into largely positive, or largely negative in tone.

The coding frame is shown in Table 5.6.

**Table 5.6. Detailed set of codes used for reporting**

Theme	Description/Notes	Code
Staffing levels	Comments relating to overall staffing, e.g. "more nurses needed"; "staff are under too much pressure".	1
Nursing staff	General comments about nurses, e.g. "nursing staff were fantastic"; "some of the nurses were unfriendly".	2
Doctors or consultants	General comments about doctors, consultants or surgeons, e.g. "my doctor was very kind"; "the surgeon and her team were great".	3
Other healthcare staff	General comments about other healthcare staff such as physios, dieticians, OTs, care assistants [note that specific healthcare staff may be anonymised], e.g. "the [healthcare professional] was excellent".	4
Other staff, e.g. cleaner, admin	General comments about other staff not covered above, e.g. "the cleaners were careless"; "the admin staff were very friendly".	5
General staff comment	Comments about staff in general without mentioning specific staff, e.g. "the staff were great".	6
Dignity, respect and privacy	Comments that refer to being treated in such a way as to maintain dignity, respect and personal privacy, particularly when related to medical or other personal information. Privacy could refer either to the patient or to overhearing information about another patient,	7



	e.g. "I just didn't feel listened to"; "on discharge, I really felt that they took my needs into account"; "there is little or no regard for privacy"; "when the nurses talked with me, they pulled the curtain and used a low voice, which was appreciated"; "was very uncomfortable on mixed sex ward with my particular condition".	
Communication: patient	As distinct from comments about staff (codes 1-6), this relates mainly to staff-patient communication; staff-staff communication is also covered here, e.g. "I was not told how my operation went"; "I was able to ask the doctor all the questions I had"; "I was hearing different opinions from different members of staff".	8
Communication: Family/relative/friend	This relates to communication between staff and family or friends of the patient, e.g. "my husband was not told when I was to be discharged"; "my family had a lot of questions about my aftercare and were not given enough time to ask them".	9
Physical comfort	Covers noise levels, pain management and other aspects of physical comfort. As distinct from privacy, it includes loud TV, noisy visitors, a sense of security, heat, light levels, etc. For example, "the patient next to me was moaning in pain and I couldn't get any sleep", "the staff were very attentive and made sure that I was comfortable".	10
ED management/ environment	Relates specifically to the emergency department environment, e.g. "the emergency department felt chaotic"; "some of the people in casualty were drunk and abusive and the staff were not able to control them".	11
ED waiting times	Relates specifically to waiting times (key word: trolley) from emergency department to ward, e.g. "I had to wait about 36 hours on a trolley before I got onto a ward".	12
Planned procedures waiting times	Relates to being on a waiting list for any planned procedure (test, operation etc.), including cancellations, e.g. "the waiting lists for [procedure name] are unacceptable – I was waiting 18 months".	13
Food and drink	Quality of food and drink provided to patients, e.g. "the food was good", "there was a vegetarian option"; "the water jugs are not refilled and impossible to get to if you are bed bound!"	14
Staff availability and responsiveness	Covers aspects such as call bell waiting times, bed pan care, help with self-care tasks, e.g. "the nurses were slow to respond to call bells – they were rushed off their feet" (this example would be coded 15 and 1).	15
Discharge and aftercare management	Relates to both information provided (e.g. medication explanations and side effects) and to management of discharge (e.g. wait times), e.g. "I got a discharge pack which explained everything, which was really good because I couldn't take in the information at the time"; "I was given four different medications with no explanation about what they were for and no indication of side effects".	16
Cleanliness or hygiene	Any comments relating to hygiene of toilets, ward environment, or hospital in general, e.g. "toilets in A&E were filthy"; "toilets on the ward were spotless"; "the ward was spotless"; "cleaners used the same cloth for cleaning all surfaces!!"; "I saw traces of blood on the floor".	17
Hospital facilities	Any comments relating to the facilities within the hospital, including quality of the building or space, e.g. "the canteen was really good – good opening hours and nice choice of food at affordable prices"; "as a patient staying here for 3 weeks I would have appreciated	18

	some activities other than a shared TV"; "A&E is in a prefab and it's damp and not fit for purpose"; "hospital is totally overcrowded".	
Parking facilities	Any comments relating to parking, e.g. "impossible to find a parking space"; "there should be a weekly permit to save on cost".	19
Clinical information/medical history/medication dosage	Comments relating to poor handling of clinical or medical details, e.g. "wrong chart was used", "chart was lost", "medical history not taken into account", "wrong medication/wrong dosage of medication given".	20
Health insurance	Comments relating to a respondent with private health insurance and the care they received or did not receive, e.g. "was entitled to private room or ward but did not get one", "was billed for private care but was on public ward or corridor", "was forced in A&E to sign health insurance form but the insurance company said not to sign a form until discharged".	21
General comment	Very general statements, either positive or negative, that are not detailed enough to include under any of the codes above, e.g. "my experience was good", "happy with my care", "medical procedure went well", "excellent treatment", "terrible experience", "awful hospital".	22
Other	Any other comments that do not readily fit under the above categories.	23

For analysis and reporting, several of the categories were collapsed into a reduced set of 10 codes. The more detailed, as well as the reduced set of codes, were used to display the results of the qualitative analysis in the online reporting platform (for more information on the online reporting platform refer to Chapter 6). Reduced coding categories were also used in individualised hospital reports, where reporting was based on a subset of comments. The reduced set of codes is shown in Table 5.7.

**Table 5.7. Reduced set of codes used for reporting of Q59-Q61**

<b>Theme</b>	<b>Description/Notes</b>	<b>Code</b>
Staffing levels and staff responsiveness (codes 1 and 15 in Table 6.6)	Comments relating to overall staffing, and to issues such as call bell waiting times, bed pan care, help with self-care tasks, e.g. "more nurses needed"; "staff are under too much pressure"; "the nurses were slow to respond to call bells".	1
Hospital staff (doctors, nurses, other healthcare staff, other staff) (codes 2, 3, 4, 5, 6 in Table 6.6)	General comment about any hospital staff, e.g. "nursing staff were fantastic"; "my doctor was very abrupt"; "the cleaners were careless"; "the receptionist was really kind".	2
Physical environment (codes 7 and 10 in Table 6.6)	Comments about management of pain and references to being treated in such a way as to maintain dignity, respect and personal privacy and	3

	or physical comfort, e.g. "I felt that they respected my privacy as best they could"; "I was very uncomfortable on mixed sex ward with my particular condition"; "the ward was extremely hot and noisy".	
Communication (codes 8 and 9 in Table 6.6)	Staff-patient, staff-staff and staff-family communication, e.g. "I was able to ask the doctor all the questions I had"; "I was hearing different opinions from different members of staff"; "my family had a lot of questions about my aftercare and were not given enough time to ask them".	4
ED environment or waiting times (codes 11 and 12 in Table 6.6)	Relates specifically to emergency department environment or waiting times, e.g. "the emergency department felt chaotic"; "some of the people in casualty were drunk and abusive and the staff were not able to control them"; "I had to wait about 36 hours on a trolley before I got onto a ward".	5
Planned procedures waiting times (code 13 in Table 6.6)	Relates to being on a waiting list for any planned procedure (test, operation etc.), including cancellations, e.g. "the waiting lists for [procedure name] are unacceptable – I was waiting 18 months".	6
Food and drink (code 14 in Table 6.6)	Quality of food and drink provided to patients, e.g. "the food was good", "there was a vegetarian option"; "the water jugs are not refilled and impossible to get to if you are bed bound!"	7
Discharge and aftercare management (code 16 in Table 6.6)	Relates to both information provided (e.g. medication explanations and side effects) and to management of discharge (e.g. wait times), e.g. "I got a discharge pack which explained everything which was really good because I couldn't take in the information at the time"; "I was given four different medications with no explanation about what they were for and no indication of side effects".	8
Cleanliness or hygiene (code 17 in Table 6.6)	Any comments relating to the hygiene of toilets, the ward environment, or the hospital in general, e.g. "toilets in A&E were filthy"; "toilets on the ward were spotless"; "the ward was spotless"; "cleaners used the same cloth for cleaning all surfaces!!"; "I saw traces of blood on the floor".	9

General or other comment (codes 20, 21, 22 and 23 in Table 6.6)	Very general statements, either positive or negative, that are not detailed enough to include under any of the codes above or any other comments that do not readily fit into the above categories, e.g. "my experience was good"; "happy with my care"; "medical procedure went well"; "excellent treatment"; "terrible experience"; "awful hospital".	10
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## 5.5. Treatment of duplicates

Duplicates could occur within the National Patient Experience Survey data in two senses: the first sense was within the data extracts, and the second was within the survey responses, whereby a respondent may have opted to complete a survey online as well as on paper.

The vast majority of duplicates within the data extracts were identified and removed as part of the quality assurance of these data. Duplicate records were discounted from the weekly extracts for repeat admissions to the same hospital and internal transfers. However, individuals who were transferred between hospitals received a survey questionnaire for each hospital to which they were admitted to. Similarly, individuals who were independently admitted to multiple hospitals during the survey month received a survey invitation for every hospital from which they were discharged.

Duplicates in the survey response file could not occur, as the system did not permit entry of a record with a survey ID already in the online survey response set. In this sense, a duplicate is defined as a paper-based response that already appears in the online file, i.e. the record in the duplicate set with the older time-stamp was the one retained in the final dataset. In reality, there were very few duplicates (amounting to less than 0.5%).

## 5.6. Quality assurance of qualitative data

Three sets of processes assured the quality of these data:

- regular audits of paper-based responses against the data entered online confirmed high levels of accuracy in the transcription of the handwritten comments to the online system.
- second, the National Patient Experience Survey team at HIQA reviewed all comments in a secure area of the online system to confirm that all anonymisation had been correctly and completely applied prior to releasing

the data to the online reporting facility (discussed in Chapter 6).

- third, 3% of responses were selected for blind double-coding. Responses were selected at a random starting point, followed by every 9th record, in order to achieve the set quota. Where necessary, codes were edited or additional codes added in order to ensure that the coding was as comprehensive as possible.

# 6. Reporting phase

## Summary

### Reporting phase (May 2017 –January 2018)

During the reporting phase, the National Patient Experience Survey team published a national, six hospital group and 39 individual hospital reports, all of which were made publically available on [www.patientexperience.ie](http://www.patientexperience.ie). The national and hospital reports were officially published on 11 December 2017.

### 6.1. Aims of the reporting phase

The aims of the reporting phase were to:

- publish national, hospital group and hospital reports
- provide hospital personnel and other stakeholders with access to a 'real-time' online reporting platform
- plan for quality improvement.

### 6.2. Content of national, hospital group and hospital reports

Reporting principles for the National Patient Experience Survey were informed by a review of national (and, where available, sub-national) reporting of patient experience surveys in Canada (British Columbia<sup>8</sup>), Scotland<sup>9</sup>, England<sup>10</sup>, Denmark (English language only)<sup>11</sup> and New Zealand.<sup>12 13</sup>

Taken together, the national, hospital group and hospital reports were designed to:

- provide a clear description of the key features of inpatient experience at

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<sup>8</sup> [http://www.health.gov.bc.ca/library/publications/year/2008/acuteinpatient\\_surveysumm.pdf](http://www.health.gov.bc.ca/library/publications/year/2008/acuteinpatient_surveysumm.pdf); <http://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/patient-experience-survey-results>

<sup>9</sup> <http://www.gov.scot/Resource/0050/00504883.pdf>  
<http://www.gov.scot/Resource/0047/00473006.pdf>

<sup>10</sup> <http://www.nhssurveys.org/surveys/833>

<sup>11</sup> [http://patientoplevelser.dk/files/dokumenter/artikel/lup\\_pixi\\_uk.pdf](http://patientoplevelser.dk/files/dokumenter/artikel/lup_pixi_uk.pdf)

<sup>12</sup> <http://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/health-quality-and-safety-indicators/patient-experience/adult-inpatient-experience/>

<sup>13</sup> These are the same countries included in the international review of patient experience survey models published by HIQA in October 2016 (<https://www.patientexperience.ie/app/uploads/2017/03/International-review-on-the-use-of-patient-experience-surveys-in-the-acute-sector.pdf>), with the addition of Canada (British Columbia).

national and local levels, pointing to areas of good experience and areas needing improvement in the system at national, hospital group and hospital levels

- together with other data and information sources, provide a robust basis for the development of quality improvement plans at hospital group and hospital levels
- enable, with other data and information sources, the identification of policy priorities at the national level
- provide a basis for benchmarking progress over time following future iterations of the survey.

The reports focused on painting a national picture of the results with comparisons of important sub-groups of the inpatient hospital population.

Comparisons of sub-groups in the national report focused on gender, age group and hospital group. The report included a visual display summarising national areas of good experience and areas needing improvement. The hospital reports were similar in structure to the national report, but compared hospital averages to the national average. The hospital group reports, published in February 2018, focused on comparing hospital groups and individual hospitals within groups.

All published reports can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

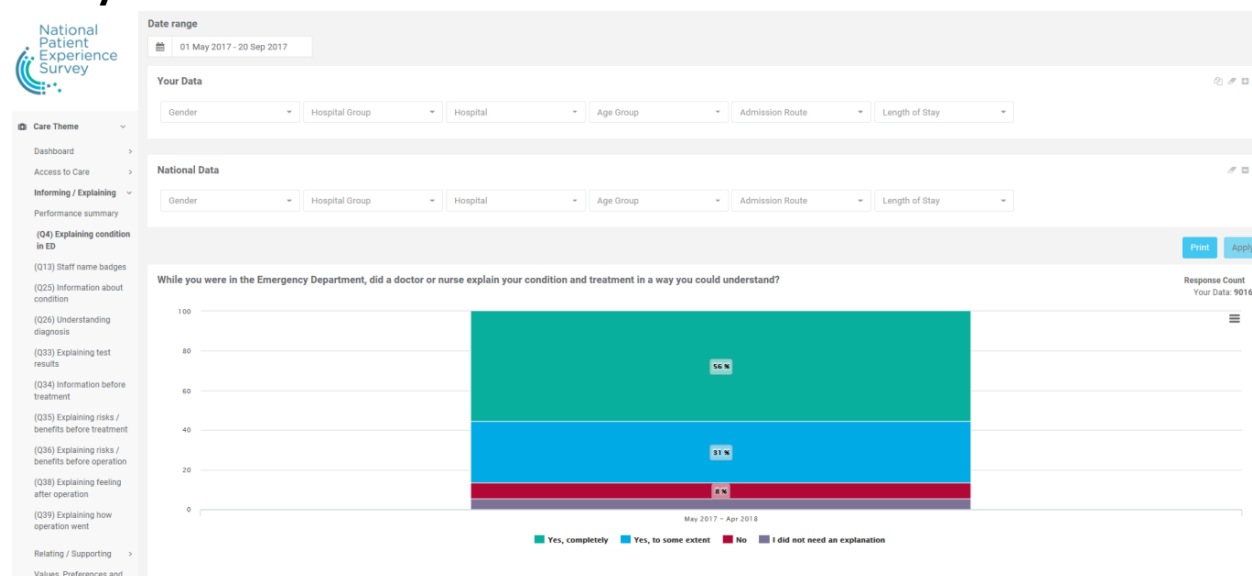
### **6.3. The National Patient Experience Survey Dashboard**

An online reporting platform (survey dashboard) was developed to allow authorised national, hospital and hospital group personnel to view their performance in real time, that is after the survey responses had been processed and open-ended responses anonymised at the back-end.

Results were only visible for hospitals with more than 30 responses. This threshold was set to preserve the privacy of all respondents, particularly those discharged from smaller hospitals. The dashboard displays all survey results in the aggregate with the exception of the anonymised open ended comments which are shown individually. A user guide and dashboard access policy were developed to support and guide the use of these online tools.

With access to real-time responses, hospitals and hospital groups did not have to wait for the publication of the reports, but rather, could track their own responses and action specific areas in need of improvement while the survey was still ongoing. The survey dashboard also allowed hospitals to review the anonymised qualitative comments submitted by respondents, thereby supplementing survey data with important contextual insights into what matters to patients during their hospital care.

**Figure 6.1. Example of online reporting platform data visualisation of survey results**



## 6.4. Comparisons with international data

One of the objectives of the National Patient Experience Survey is to use the survey results to compare the performance of the Irish healthcare system with other jurisdictions. Inpatient surveys are undertaken in a number of countries, using a wide variety of approaches and survey tools. Comparing patient experience across jurisdictions is challenging due to variations in health service provision, differences in survey instruments and methodology, as well as cultural differences in how encounters with the health service are perceived and reported.<sup>(19, 20)</sup>

Nevertheless, there are some commonalities in survey approaches across jurisdictions and comparison of results on similar questions can provide useful context. This brief review compares results from the National Patient Experience Survey with the findings of inpatient surveys conducted in England, Scotland and New Zealand. A summary of the approaches taken in each jurisdiction and how they compare with the National Patient Experience Survey approach is provided in Table 6.1.



**Table 6.1.: Overview of adult inpatient experience surveys in Scotland, England and New Zealand.**

<b>Jurisdiction</b>	<b>Survey information</b>	<b>Differences to NPE Survey approach</b>
Scotland	Scottish Inpatient Experience Survey 2016 Questions on: <ul style="list-style-type: none"> <li>• admission to hospital</li> <li>• the hospital and ward</li> <li>• care and treatment</li> <li>• hospital staff</li> <li>• arrangements for leaving hospital</li> <li>• care and support services after leaving hospital.</li> </ul>	Wider coverage of hospitals, not just acute general.  Participants between 16 and 18 years of age included.
England	Adult inpatient survey 2016 (NHS data published via CQC) Excluding maternity. Questions under domains of patient experience: <ul style="list-style-type: none"> <li>• access and waiting</li> <li>• safe, high-quality, co-ordinated care</li> <li>• better information, more choice</li> <li>• building closer relationships</li> <li>• clean, friendly, comfortable place to be.</li> </ul>	Wider coverage of hospitals, not just acute general.  Participants between 16 and 18 years of age included.
New Zealand	HQSC adult inpatient survey (quarterly survey). Most recent results — August 2017 20 Questions under domains of: <ul style="list-style-type: none"> <li>• communication</li> <li>• partnership</li> <li>• coordination</li> <li>• physical and emotional needs.</li> </ul>	Data collected four times annually.  Online data collection primarily.  Participants between 15 and 18 years of age included.

A comparison of results across selected questions is provided in Table 6.2. Comparisons are only made for those questions with identical wording and response options across the various national surveys. In Table 2, questions are numbered and ordered according to where they appear in the National Patient Experience Survey. These questions may be numbered and categorised differently in the other surveys.

**Table 6.2. Comparison of question scores across jurisdictions.**

	Ireland (2017)	Scotland (2016)	England (2016)	NZ (May 2017)
Response rate	51%	40%	44%	24%
Sex (female %)	51%	57%	53%	58%

Admission route (emergency %)	72%	63%	61%	Not reported
Age (>65%)	51%	59%	63%	47%
Q52. Overall, did you feel you were treated with respect and dignity while you were in the hospital? (% yes, always)	83%	Not reported	84%	88%
Q53. Overall rating of hospital experience (% who gave rating between 7 and 10)	84%	84%	86%	Not reported

## 6.5. Survey findings, quality improvement and next steps

The HSE is leading on the responses of service providers to the National Patient Experience Survey results. The implementation of quality improvement initiatives, in response to the survey findings, is an objective of National Patient Experience Survey Programme. The development of a national quality improvement plan was initiated in June 2017.

A quality improvement oversight group was formed in August 2017. The group facilitated a series of planning workshops with hospital groups in 2017, enabling discussion about the key quality improvement priorities.

A national quality improvement plan was officially released by the HSE on 11 December 2017, which coincided with the launch and publication of the survey results. The national quality improvement plan includes six hospital group plans and individual hospital plans. The HSE Acute Hospital Division has committed to the monitoring of the implementation of the quality improvement plans.

The quality improvement plans for each hospital and hospital group can be downloaded from [www.patientexperience.ie](http://www.patientexperience.ie).

# Appendix 1

## Complete question set of the National Patient Experience Survey 2017

No.	Question
1.	Was your most recent hospital stay planned in advance or an emergency?
2.	When you arrived at the hospital, did you go to the Emergency Department (also known as the A&E Department or Casualty)?
3.	When you had important questions to ask doctors and nurses in the Emergency Department, did you get answers that you could understand?
4.	While you were in the Emergency Department, did a doctor or nurse explain your condition and treatment in a way you could understand?
5.	Were you given enough privacy when being examined or treated in the Emergency Department?
6.	Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?
7.	Did you remain in the Emergency Department for the entire time of your stay?
8.	Following arrival at the hospital, how long did you wait before being admitted to a ward?
9.	Were you given enough privacy while you were on the ward?
10.	In your opinion, how clean was the hospital room or ward that you were in?
11.	How clean were the toilets and bathrooms that you used in hospital?
12.	When you needed help from staff getting to the bathroom or toilet, did you get it in time?
13.	Did staff wear name badges?
14.	Did the staff treating and examining you introduce themselves?
15.	How would you rate the hospital food?

<b>16.</b>	Were you offered a choice of food?
<b>17.</b>	Were you ever unable to eat during mealtimes (e.g. because you were away from the ward, recovery from surgery etc.)?
<b>18.</b>	Were you offered a replacement meal at another time?
<b>19.</b>	Did you get enough help from staff to eat your meals?
<b>20.</b>	When you had important questions to ask a doctor, did you get answers that you could understand?
<b>21.</b>	Did you feel you had enough time to discuss your care and treatment with a doctor?
<b>22.</b>	When you had important questions to ask a nurse, did you get answers that you could understand?
<b>23.</b>	If you ever needed to talk to a nurse, did you get the opportunity to do so?
<b>24.</b>	Were you involved as much as you wanted to be in decisions about your care and treatment?
<b>25.</b>	How much information about your condition or treatment was given to you?
<b>26.</b>	Was your diagnosis explained to you in a way that you could understand?
<b>27.</b>	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
<b>28.</b>	Did you find someone on the hospital staff to talk to about your worries and fears?
<b>29.</b>	Did you have confidence and trust in the hospital staff treating you?
<b>30.</b>	Were you given enough privacy when discussing your condition or treatment?
<b>31.</b>	Were you given enough privacy when being examined or treated?
<b>32.</b>	Do you think the hospital staff did everything they could to help control your pain?
<b>33.</b>	Did a doctor or nurse explain the results of the tests in a way that you could understand?
<b>34.</b>	Before you received any treatments did a member of staff explain what would happen?
<b>35.</b>	Before you received any treatments did a member of staff explain any risks and/or benefits in a way you could understand?

<b>36.</b>	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?
<b>37.</b>	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?
<b>38.</b>	Beforehand, were you told how you could expect to feel after you had the operation or procedure?
<b>39.</b>	After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?
<b>40.</b>	Did you feel you were involved in decisions about your discharge from hospital?
<b>41.</b>	Were you given enough notice about when you were going to be discharged?
<b>42.</b>	Were your family or someone close to you given enough notice about your discharge?
<b>43.</b>	Before you left hospital, did the healthcare staff spend enough time explaining about your health and care after you arrive home?
<b>44.</b>	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?
<b>45.</b>	Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?
<b>46.</b>	Did a member of staff tell you about medication side effects to watch for when you went home?
<b>47.</b>	Did a member of staff tell you about any danger signals you should watch for after you went home?
<b>48.</b>	Did hospital staff take your family or home situation into account when planning your discharge?
<b>49.</b>	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?
<b>50.</b>	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
<b>51.</b>	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?
<b>52.</b>	Overall, did you feel you were treated with respect and dignity while you were in the hospital?
<b>53.</b>	Overall... (please circle a number from 0 to 10 that summarises your experience. 0 represents a very poor experience, 10 represents a very good experience.)
<b>54.</b>	Who was the main person or people that filled in this questionnaire?
<b>55.</b>	Are you male or female?

<b>56.</b>	What is your month and year of birth?
<b>57.</b>	What is your ethnic or cultural background?
<b>58.</b>	Do you currently have: A medical card; Private health insurance; Both medical card and private health insurance; Neither medical card nor private health insurance
<b>59.</b>	Was there anything particularly good about your hospital care?
<b>60.</b>	Was there anything that could be improved?
<b>61.</b>	Any other comments or suggestions?

## Appendix 2

**2017 question wording, response options, corresponding scores and mapping to aspects and stages of care**

	<b>Question wording</b>	<b>Response options and scoring (M = Missing)</b>	<b>Aspect of Care</b>	<b>Stage of Care</b>
Q03	When you had important questions to ask doctors and nurses in the Emergency Department, did you get answers that you could understand?	Yes, always (10) Yes, sometimes (5) No (0) I had no need to ask/I was too unwell to ask questions (M)	Relating/supporting	Admissions
Q04	While you were in the Emergency Department, did a doctor or nurse explain your condition and treatment in a way you could understand?	Yes, completely (10) Yes, to some extent (5) No (0) I did not need an explanation (M)	Informing/explaining	Admissions
Q05	Were you given enough privacy when being examined or treated in the Emergency Department?	Yes, definitely (10) Yes, to some extent (5) No (0) Don't know/can't remember (M)	Values, preferences and needs	Admissions
Q06	Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?	Yes, always (10) Yes, sometimes (5) No (0)	Values, preferences and needs	Admissions
Q08	Following arrival at the hospital, how long did you wait before being admitted to a ward?	Less than 6 hours (10) Between 6 and up to 12 hours (7.5) Between 12 and up to 24 hours (5) Between 24 and up to 48 hours (2.5) More than 48 hours (0) Don't know/can't remember (M) I was not admitted to a ward (M)	Access to care	Admissions



Q09	Were you given enough privacy when you were on the ward?	Yes, always (10) Yes, sometimes (5) No (0)	Values, preferences and needs	Care on the ward
Q10	In your opinion, how clean was the hospital room or ward that you were on?	Very clean (10) Fairly clean (6.67) Not very clean (3.33) Not at all clean (0)	Physical comfort	Care on the ward
Q11	How clean were the toilets and bathrooms that you used in hospital?	Very clean (10) Fairly clean (6.67) Not very clean (3.33) Not at all clean (0) I did not use a toilet or bathroom (M)	Physical comfort	Other
Q12	When you needed help from staff getting to the bathroom or toilet, did you get it in time?	Yes, always (10) Yes, sometimes (5) No (0) I did not need help (M)	Physical comfort	Care on the ward
Q13	Did staff wear name badges?	Yes, all of the staff wore name badges (10) Some of the staff wore name badges (5) Very few or none of the staff wore name badges (0) Don't know/can't remember (M)	Informing/explaining	Care on the ward
Q14	Did the staff treating and examining you introduce themselves?	Yes, all of the staff introduced themselves (10) Some of the staff introduced themselves (5) Very few or none of the staff introduced themselves (0) Don't know/can't remember (M)	Values, preferences and needs	Care on the ward
Q15	How would you rate the hospital food?	Very good (10) Good (6.67) Fair (3.33) Poor (0) I did not have any hospital food (M)	Physical comfort	Care on the ward
Q16	Were you offered a choice of food?	Yes, always (10) Yes, sometimes (5) No (0)	Physical comfort	Care on the ward

Q18	Were you offered a replacement meal at another time?	Yes, always (10) Yes, sometimes (5) No (0) I did not want a meal (M) I was not allowed a meal (e.g. because I was fasting) (M)	Physical comfort	Care on the ward
Q19	Did you get enough help from staff to eat your meals?	Yes, always (10) Yes, sometimes (5) No (0) I did not need help to eat meals (M)	Physical comfort	Care on the ward
Q20	When you had important questions to ask a doctor, did you get answers that you could understand?	Yes, always (10) Yes, sometimes (5) No (0) I had no need to ask (M)	Relating/supporting	Care on the ward
Q21	Did you feel you had enough time to discuss your care and treatment with a doctor?	Yes, definitely (10) Yes, to some extent (5) No (0)	Relating/supporting	Examination/Diagnosis/Treatment
Q22	When you had important questions to ask a nurse, did you get answers that you could understand?	Yes, always (10) Yes, sometimes (5) No (0) I had no need to ask (M)	Relating/supporting	Care on the ward
Q23	If you ever needed to talk to a nurse, did you get the opportunity to do so?	Yes, always (10) Yes, sometimes (5) No (0) I had no need to talk to a nurse (M)	Relating/supporting	Care on the ward
Q24	Were you involved as much as you wanted to be in decisions about your care and treatment?	Yes, definitely (10) Yes, to some extent (5) No (0)	Values, preferences and needs	Examination/Diagnosis/Treatment
Q25	How much information about your condition or treatment was given to you?	Not enough (0) The right amount (10) Too much (0)	Informing/explaining	Examination/Diagnosis/Treatment
Q26	Was your diagnosis explained to you in a way that you could understand?	Yes, completely (10) Yes, to some extent (5) No (0)	Informing/explaining	Examination/Diagnosis/Treatment

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 (10) Yes, to some extent (5) No (0) No family or friends were involved (M) My family did not want or need information (M) I did not want my family or friends to talk to a doctor (M)	Relating/supporting	Other
Q28	Did you find someone on the hospital staff to talk to about your worries and fears?	Yes, definitely (10) Yes, to some extent (5) No (0) I had no worries or fears (M)	Relating/supporting	Care on the ward
Q29	Did you have confidence and trust in the hospital staff treating you?	Yes, always (10) Yes, sometimes (5) No (0)	Relating/supporting	Other
Q30	Were you given enough privacy when discussing your condition or treatment?	Yes, always (10) Yes, sometimes (5) No (0)	Values, preferences and needs	Examination/Diagnosis/Treatment
Q31	Were you given enough privacy when being examined or treated?	Yes, always (10) Yes, sometimes (5) No (0)	Values, preferences and needs	Examination/Diagnosis/Treatment
Q32	Do you think the hospital staff did everything they could to help control your pain?	Yes, definitely (10) Yes, to some extent (5) No (0) I was never in any pain (M)	Physical comfort	Care on the ward
Q33	Did a doctor or nurse explain the results of the tests in a way that you could understand?	Yes, definitely (10) Yes, to some extent (5) No (0) Not sure/can't remember (M) I was told I would get the results at a later date (M) I was never told the results of tests (M) I did not have any tests (M)	Informing/explaining	Examination/Diagnosis/Treatment
Q34	Before you received any treatments did a member of staff explain what would happen?	Yes, always (10) Yes, sometimes (5) No (0) I did not want an explanation (M) I did not have any treatments (M)	Informing/explaining	Examination/Diagnosis/Treatment

Q35	Before you received any treatments did a member of staff explain any risks and/or benefits in a way you could understand?	Yes, always (10) Yes, sometimes (5) No (0) I did not want an explanation (M)	Informing/explaining	Examination/Diagnosis/Treatment
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 (10) Yes, to some extent (5) No (0) I did not want an explanation (M) I did not have an operation or procedure (M)	Informing/explaining	Examination/Diagnosis/Treatment
Q37	Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?	Yes, completely (10) Yes, to some extent (5) No (0) I did not have any questions (M)	Relating/supporting	Examination/Diagnosis/Treatment
Q38	Beforehand, were you told how you could expect to feel after you had the operation or procedure?	Yes, completely (10) Yes, to some extent (5) No (0)	Informing/explaining	Examination/Diagnosis/Treatment
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 (10) Yes, to some extent (5) No (0)	Informing/explaining	Examination/Diagnosis/Treatment
Q40	Did you feel you were involved in decisions about your discharge from hospital?	Yes, definitely (10) Yes, to some extent (5) No (0) I did not want to be involved (M)	Values, preferences and needs	Discharge/transfers
Q41	Were you given enough notice about when you were going to be discharged?	Yes, definitely (10) Yes, to some extent (5) No (0)	Continuity and transition	Discharge/transfers

Q42	Were your family or someone close to you given enough notice about your discharge?	Yes, definitely (10) Yes, to some extent (5) No (0) No family or friends were involved (M) Don't know/can't remember (M)	Continuity and transition	Discharge/transfers
Q43	Before you left hospital, did the hospital staff spend enough time explaining about your health and care after you arrive home?	Yes (10) No (0)	Continuity and transition	Discharge/transfers
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 (10) No (0)	Continuity and transition	Discharge/transfers
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 (10) Yes, to some extent (5) No (0) I did not need an explanation (M) I had no medicines (M)	Continuity and transition	Discharge/transfers
Q46	Did a member of staff tell you about medication side effects to watch for when you went home?	Yes, completely (10) Yes, to some extent (5) No (0) I did not need an explanation (M)	Continuity and transition	Discharge/transfers
Q47	Did a member of staff tell you about any danger signals you should watch for after you went home?	Yes, completely (10) Yes, to some extent (5) No (0) It was not necessary (M)	Continuity and transition	Discharge/transfers
Q48	Did hospital staff take your family or home situation into account when planning your discharge?	Yes, completely (10) Yes, to some extent (5) No (0) Don't know/can't remember (M)	Continuity and transition	Discharge/transfers

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 (10) Yes, to some extent (5) No (0) No family or friends were involved (M) My family or friends did not want or need information (M)	Relating/supporting	Discharge/transfers
Q50	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Yes (10) No (0) Don't know/can't remember (M)	Continuity and transition	Discharge/transfers
Q51	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?	Yes, definitely (10) Yes, to some extent (5) No (0) I did not need help in managing my condition (M)	Continuity and transition	Discharge/transfers
Q52	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Yes, always (10) Yes, sometimes (5) No (0)	Values, preferences and needs	Other
Q53	Overall... (please circle a number)	I had a very poor experience (0) to I had a very good experience (10)	Overall	Overall

## Appendix 3

### Discharge, invitation, reminder and sympathy letter templates

#### [Letter 1 – discharge letter]

May 2017

### Please help us make hospital care better

Dear Sir or Madam,

Three national healthcare organisations, the Health Service Executive (HSE), the Health Information and Quality Authority (HIQA) and the Department of Health have come together to carry out a nationwide survey asking people for their views on their hospital care. This is the first of its kind in Ireland.

The **National Patient Experience Survey** asks people for feedback on their recent stay in hospital. The results of the survey will be used to improve the quality of hospital care across the country.

On behalf of the three organisations, I am writing to let you know that you may be invited to take part in the survey. Adult patients who have spent one or more nights in a public hospital and who have been discharged in May 2017 will receive a survey in the post about two weeks after they leave hospital.

Participation is voluntary, and all responses are anonymous. The 20-minute questionnaire can be completed online or using the paper version sent by post.

A research organisation called Behaviour & Attitudes is carrying out this survey on behalf of the HSE, HIQA and the Department of Health. Behaviour & Attitudes will securely hold the names and addresses of people selected to take part in the survey. Contact details are only used *to send out the survey and* will be deleted at the end of July 2017.

You can find more information on the National Patient Experience Survey at **[www.patientexperience.ie](http://www.patientexperience.ie)**. If you have any questions or concerns about the survey you can contact us at **[info@patientexperience.ie](mailto:info@patientexperience.ie)**, or call our Freephone number on **1800 314093** (Monday-Friday, 9am-5pm).

Thank you for taking the time to read this letter.

Yours faithfully,

**Tony O'Brien**  
Director General  
Health Service Executive (HSE)

**[Letter 2 – invitation letter]**

[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](http://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)

## [Letter 3 – first reminder]

[Date]

**Survey Code:** [Survey Code]

**Hospital Name:** [Hospital Name]

### Please help us make hospital care better

Dear [Name],

About two weeks ago, you received an invitation to take part in the National Patient Experience Survey to tell us about your care in [**Hospital Name**]. We haven't received your response yet and would really like your feedback to help us understand what your care was like. Even if your stay in hospital was short, we'd like to hear your views.

If you've already completed the survey, thank you, and please accept our apologies for sending this reminder.

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 required).

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).

Taking part in the survey is voluntary and it should only take about 20 minutes. The survey is anonymous. Your individual results are never reported.

If you do not want to take part in this survey and would prefer not to receive another 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. By participating in this survey, you

are helping to improve care for patients in Ireland.

Thank you for taking the time to read this letter.

Yours sincerely,

**Tony O'Brien**

Director General  
Health Service Executive (HSE)

### [Letter 4 – second reminder]

[Date]

**Survey Code:** [Survey Code]

**Hospital Name:** [Hospital Name]

## Please help us make hospital care better

Dear [Name],

About four weeks ago, we sent you a questionnaire, inviting you to take part in the National Patient Experience Survey to tell us about the care you received in **[Hospital Name]**. All adult patients who spent one or more nights in a public hospital in Ireland and who were discharged in May have been invited to take part.

We haven't received your response yet and would really like your feedback. Hearing about your experience will help us improve experience for all patients. If you've already returned your questionnaire, thank you, and please accept our apologies for sending this reminder.

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 required), if possible within **two weeks** of receiving this letter.

We can receive questionnaires online or by post up until **26 July 2017**.

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).

Taking part 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.

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.

We would like to hear your views, even if you only stayed in hospital for a short time.

Thank you for taking the time to read this letter.

Yours sincerely,

**Tony O'Brien**

Director General  
Health Service Executive (HSE)

## [Letter 5 - Sympathy letter]

[Address 1]

[Address 2]

[Address 3]

[Address 4]

[Address 5]

[Date]

Dear [Relative Name],

I understand that you received an invitation for [Patient Name] to take part in the National Patient Experience Survey. Please accept my sincere apologies. I would like to convey my deepest sympathies to you and your loved ones following your recent loss.

Following your communication with the National Patient Experience Survey team we will update our records to ensure that you do not receive any further correspondence addressed to [Patient Name].

Again, please accept my condolences.

Yours sincerely,

**Tony O'Brien**

Director General  
Health Service Executive (HSE)

## Appendix 4

### Operational outcomes and response rates by hospital group and individual hospital

	Total discharged	Deceased	Opted-out	No-response	Completed on paper	Completed online	Response rate (%)
<b>Dublin Midlands Hospital group</b>	<b>4973</b>	<b>76</b>	<b>88</b>	<b>2362</b>	<b>2219</b>	<b>227</b>	<b>50%</b>
Midland Regional Hospital Portlaoise	475	16	6	233	207	13	48%
Midland Regional Hospital Tullamore	845	20	9	393	388	35	51%
Naas General Hospital	598	10	12	298	253	25	47%
St. James Hospital	1684	12	37	793	757	84	50%
Tallaght Hospital	1371	19	23	645	614	70	51%
<b>Ireland East Hospital Group</b>	<b>5725</b>	<b>64</b>	<b>107</b>	<b>2617</b>	<b>2665</b>	<b>272</b>	<b>52%</b>
Cappagh National Orthopaedic Hospital	239	0	0	68	152	19	72%
Mater Misericordiae University Hospital	1186	4	18	572	528	64	50%
Midland Regional Hospital Mullingar	638	6	15	314	283	20	48%
Our Lady's Hospital	332	0	14	134	174	10	55%
Royal Victoria Eye and Ear Hospital	162	0	1	66	86	0	53%
St. Columcille's Hospital	125	1	2	64	58	9	54%
St. Luke's General Hospital	678	15	13	330	301	19	48%
St. Michael's Hospital	245	7	1	105	116	15	55%
St. Vincent's University Hospital	1471	19	26	680	646	99	51%
Wexford General Hospital	649	12	15	284	321	17	53%
<b>RCSI Hospital Group</b>	<b>4300</b>	<b>52</b>	<b>88</b>	<b>2127</b>	<b>1825</b>	<b>208</b>	<b>48%</b>
Beaumont Hospital	1673	27	38	782	737	89	50%
Cavan and Monaghan Hospital Group	657	8	17	343	261	28	45%
Connolly Hospital	800	8	12	408	330	42	47%
Louth County Hospital*	39	1	0	21	17	0	45%
Our Lady of Lourdes*	1131	8	21	573	480	49	47%
<b>Saolta Hospital Group</b>	<b>4739</b>	<b>90</b>	<b>114</b>	<b>2123</b>	<b>2243</b>	<b>172</b>	<b>52%</b>
Galway University Hospitals	1743	17	39	777	832	78	53%
Letterkenny University Hospital	865	28	19	384	404	30	52%

Mayo University Hospital	793	16	26	369	363	19	49%
Portiuncula Hospital	432	12	7	209	191	13	49%
Roscommon County Hospital	97	1	4	39	52	1	55%
Sligo University Hospital	809	16	16	345	401	31	54%
<b>South West Hospital Group</b>	<b>5255</b>	<b>111</b>	<b>114</b>	<b>2226</b>	<b>2602</b>	<b>199</b>	<b>54%</b>
Bantry General Hospital	180	5	6	71	94	4	56%
Cork University Hospital	1687	46	33	707	835	66	55%
Kilcreene Orthopaedic Hospital	70	0	0	10	56	4	86%
Mallow General Hospital	138	2	3	51	78	4	60%
Mercy University Hospital	748	21	18	315	368	26	54%
South Infirmary Victoria University Hospital	315	3	4	88	199	21	71%
South Tipperary General Hospital	591	16	11	265	280	19	52%
University Hospital Kerry	555	7	11	269	256	12	49%
University Hospital Waterford	971	11	28	450	439	43	50%
<b>UHL Hospital Group</b>	<b>2085</b>	<b>49</b>	<b>45</b>	<b>917</b>	<b>1000</b>	<b>74</b>	<b>53%</b>
Croom Orthopaedic Hospital	126	0	3	38	79	6	67%
St. John's Hospital Limerick	217	10	6	90	103	8	54%
UL Hospitals, Ennis	147	5	5	50	81	6	61%
UL Hospitals, Nenagh	108	4	3	48	48	5	51%
University Hospital Limerick	1487	30	28	691	689	49	51%

# Appendix 5

## Guidelines for the reduction of qualitative comments

Coders were provided with the following guidelines:

- do not leave any personal names as they relate to either the respondent or any hospital staff. [Doctor], [Nurse], [Name] should be typed if names are referenced. Specialised staff should be changed, e.g. 'Orthopaedic Doctor' should be changed to [Specialist Doctor], and specific healthcare staff such as dietician, physiotherapist should be changed to [Healthcare Professional].
- do not leave ward names or ward types. Use [Ward Name] or [Ward Type]. However, do not change emergency department or operating theatre.
- do not leave any location or nationality identifiers as they relate to people such as country or county. Instead use [City], [County], [Nationality], etc. Ethnicity descriptors as well as any other attributes that could identify an individual may need to be omitted completely depending on the context, for example mention of an ethnic minority nurse in a small hospital would be replaced by [ ] nurse.
- do not leave specific conditions, such as heart attack, stroke, diabetes, or specific operations/procedures, such as bypass operation, hip replacement. For example, diabetes should be replaced with [Condition] and bypass surgery should be replaced with [Operation].
- do not leave specific medications; use [Medication] or [Treatment].
- do not leave specific dates (enter these as [Date]), but do leave days of the week.
- hospital names can be left unchanged.

For paper-based responses only, coders were also advised:

- if a portion of the response is illegible, type [...] and continue to the next legible part of the comment. Aim to get a balance between capturing the maximum amount of information possible and time spent on deciphering handwriting.
- it is possible that some respondents may continue their comments over to the back page of the questionnaire (page 12) or to the blank space on page 10. If this is the case, enter the text using common sense. If you are not sure which text box the 'extra' text relates to, use the space for Q61 to enter this information.



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