National Patient Experience Survey Programme

An overview of the National Patient Experience Survey questionnaire development process
# Table of contents

Summary .................................................................................................................................................. 3

1. About the National Patient Experience Survey ................................................................................. 5

2. The survey development process ...................................................................................................... 6

   2.1 International review ...................................................................................................................... 6

   2.2 Outcomes from the patient-led focus groups .............................................................................. 7

   2.3 Outcomes from the Delphi study .................................................................................................. 8

   2.4 Consultation meeting with Picker Institute Europe ...................................................................... 10

   2.5 Cognitive interviews ..................................................................................................................... 10

3. Conclusion .......................................................................................................................................... 12

Appendix A — A note on Picker Institute Europe ............................................................................... 13

References .............................................................................................................................................. 14
Summary

The National Patient Experience Survey seeks to capture the experiences of all adult patients discharged from public acute hospitals in May 2017. The questionnaire for the National Patient Experience Survey in Ireland was developed over many months in 2016/2017. In order ensure that the National Patient Experience Survey questionnaire would be fit-for-purpose and meaningful in the Irish healthcare context, question selection and questionnaire development were carried out in five steps.

1. An international review of patient experience surveys was conducted in 2016 to inform the content and structure of the National Patient Experience Survey. The international review found that the majority of jurisdictions reviewed used questions from Picker Institute Europe’s library. A library of 189 internationally-validated questions was subsequently purchased from Picker Institute Europe to use as a basis for the survey questionnaire in Ireland.

2. Eight focus groups were conducted. Six of the focus groups were conducted with patients, with the patients drawn from hospitals in each of Ireland’s hospital groups. Two additional focus groups were conducted with data users in both Dublin and Cork. The purpose of the focus groups was to determine which questions would be reasonable, manageable, relevant and appropriate for the Irish context.

3. A two-round Delphi study was commissioned which integrated the findings from the focus group discussions to further refine the questions for inclusion in the National Patient Experience Survey.

4. The Delphi study generated a prioritised set of 60 questions and identified an additional 40 questions ranked in order of preference. The Picker Institute Europe reviewed the results of the study and recommended a small number of changes to improve overall measurement quality.

5. A questionnaire comprising of 60 questions was tested in ten cognitive interviews with patients and patient representatives to identify any difficulties respondents may have answering questions and to identify and fix problems with layout, routing and flow of the questionnaire.

The National Patient Experience Survey questionnaire is the outcome of a robust process that integrates the results from the focus groups, the Delphi study, expert
advice received from Picker Institute Europe and feedback from cognitive interviews with patients.
1. About the National Patient Experience Survey

Evidence suggests that positive experiences as reported by patients are associated with improved health outcomes.\(^{(1)}\) In many healthcare systems, patient experience is increasingly recognised as an indicator of health care quality, alongside clinical and safety outcomes.\(^{(2)}\) This represents a shift in performance management towards a benchmarking against the quality of care as experienced by patients’ themselves. To be successful in the current era of health reform, organisations need to rethink engagement and consider patients as central to the care team.\(^{(3)}\) One way of engaging with patients and capturing their feedback is through a patient experience survey. Large-scale surveys are an effective way to engage with patients and, in so doing, help drive accountability and transparency across healthcare services.\(^{(4)}\)

The National Patient Experience Survey seeks to enhance the quality and safety of care provided to patients in Ireland by listening to the experience and feedback of adults who have spent at least one night in a public acute hospital. The results of the survey will help improve the safety and quality of services provided to patients, inform healthcare standards and help shape future healthcare policies.

A partnership programme has been set up between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health to develop and implement the National Patient Experience Survey. Patients and their representatives have also been involved throughout the survey development process. The survey will allow and enable patients to voice their opinion, to tell their story and, in doing so, provide a rich source of information that will assist all of the partner organisations to work towards improving the quality of patients’ experiences in acute healthcare.
2. The survey development process

This section outlines the various steps and methodologies involved in developing the National Patient Experience Survey questionnaire.

2.1 International review

HIQA conducted an international review\(^\text{(5)}\) of the model and methodology for patient experience surveys in Scotland, Denmark, New Zealand and England. The National Patient Experience Survey was informed by patient experience surveys successfully conducted in other countries. The review found that all international jurisdictions examined have been conducting patient experience surveys for a number of years and each one demonstrated significant benefits to all stakeholders involved, whilst keeping the patient at the forefront at all times. Furthermore, the review found that the majority of countries used internationally validated questions designed by Picker Institute Europe.*

The National Patient Experience Survey programme subsequently purchased a library of internationally-validated questions from Picker Institute Europe (the Picker Library of Questions). Designing new survey questions is a time and resource intensive process that is often unnecessary as tested and validated question banks already exist.\(^\text{(6)}\) Adopting questions that are used internationally also facilitates comparisons of patient experience across different countries.\(^\text{(6, 7)}\)

In order to ensure that the results of a survey can guide quality improvement at a national level, the survey tool (questionnaire) needs to reflect a wide array of patient experiences as they may exist in a specific context. The Picker Library of questions was tested for applicability and relevance in the Irish healthcare context through patient and data user focus groups, a Delphi study and cognitive interviews with patients and patient representatives. This multi-stage process resembles patient experience survey development practices internationally.

---

* The Picker Institute Europe was established in 2000. It is an international charity in the health and social care sector dedicated to developing a patient-centred approach to healthcare. See Appendix A for a note on Picker Institute Europe.
2.2 Outcomes from the patient-led focus groups

Between 26 May and 10 June 2016, the National Patient Experience Survey Team conducted six focus groups with patients within each of the six hospital groups. Focus groups are a form of interview conducted with “a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research” (8, p.499). A qualitative research method, the focus group permits researchers to prioritise the “meanings, views and experiences” of participants. (8, p.499)

Table 1 provides a breakdown of the focus groups by location and number of participants. The purpose of the focus groups was to:

1. Discuss the participants’ views of the frequently asked questions document, which would provide the public with information in relation to the National Patient Experience Survey.
2. Discuss the most appropriate manner in which to distribute the survey, whether by email, post or text.
3. Examine the library of 189 internationally-validated survey questions in order to identify the most appropriate questions for the Irish context.

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

<table>
<thead>
<tr>
<th>Date in 2016</th>
<th>Location</th>
<th>Number of participants</th>
<th>Number of staff met</th>
</tr>
</thead>
<tbody>
<tr>
<td>26 May</td>
<td>Limerick University Hospital (University of Limerick Hospitals Group)</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>31 May</td>
<td>University Hospital Galway (Saolta Hospital Group)</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>1 June</td>
<td>University Hospital Kerry (South/South West Hospital Group)</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>
The full library of questions was discussed by theme with each of the six patient focus groups. Focus group feedback indicated that out of the 189 internationally-validated questions, 119 should be retained for inclusion in the National Patient Experience Survey and 39 questions could be removed. A consensus could not be reached for 23 of the questions, and participants felt that eight questions could be combined.

Two additional focus groups were conducted with data users to gain an understanding of how end users value the data from the National Patient Experience Survey and what they might use it for. The feedback from the focus groups was used to inform the second round of the Delphi study. The detailed Statement of Outcomes report is available on www.patientexperience.ie.

### 2.3 Outcomes from the Delphi study

A Delphi study was commissioned by the National Patient Experience Survey Programme to reach a consensus on the refinement of the library of 189 internationally-validated questions. The Delphi technique “is a research approach used to gain consensus through a series of rounds of questionnaire surveys, usually two or three, where information and results are fed back to panel members between each round”.

A Delphi study was conducted over two rounds and integrated the findings from the focus group discussions to inform the selection of priority questions for inclusion in the National Patient Experience Survey. A panel of expertise was appointed that comprised of patients, patient advocates at hospital level, clinicians, policy.
developers, senior managers and researchers who have published peer-reviewed articles in the area of patient experience. More specifically, panel members were recruited through snowball sampling for their expertise in measurement, expertise in patient experience across a range of areas, expertise in utilising data for decision-making and their willingness to take part in the study. A total of 58 participants took part in the Delphi study.

The first round of the study sought to identify the level of consensus for individual questions by asking participants to indicate whether they felt that individual items should be included or excluded in the National Patient Experience Survey. A cut off point of 75% was adopted, that is, if more than 75% of participants did not choose a question it would not be considered a priority for inclusion. Consensus was achieved among the Delphi study participants and the patient and data user focus groups on 64 of the questions for inclusion. In the second round, participants were asked to consider the results from the focus group discussions and to indicate their agreement/disagreement with the inclusion of questions on a sliding scale from 0-100%. Questions were subsequently ranked by level of agreement.

The questions were further mapped against four of the themes from the National Standards for Safer Better Healthcare, specifically:

- Theme 1: Person Centred Care and Support Services
- Theme 2: Effective Care and Support
- Theme 3: Safe Care and Support
- Theme 4: Better Health and Wellbeing.

The Delphi study generated a set of 60 top-ranked questions as well as a reserve list of 40 questions for inclusion at a later stage in the process or in future iterations of the survey.

---

† In a snowball sampling approach, contact is made with an initial group of participants, who will subsequently identify appropriate individuals from within their own networks.
2.4 Consultation meeting with Picker Institute Europe

The literature on survey design recommends that feedback should be obtained on the draft questionnaire from survey content, structure and analysis experts to highlight “potential survey design problems”. In line with best practice and in order to ensure that the questions selected for inclusion would provide the greatest value in terms of feedback for the healthcare service, Picker Institute Europe was consulted to advise on the proposed survey questionnaire. The objective of the consultation between Picker Institute Europe and the National Patient Experience Survey Team was to discuss the results of the Delphi study. The top 100 questions were individually discussed and evaluated on the basis of their rationale for inclusion and usefulness in the final survey questionnaire.

Given the considerable expertise of Picker Institute Europe in conducting patient experience surveys, this meeting presented a useful opportunity to review the survey design process to date, to learn from the Institute’s practical experience and to refine the questions for inclusion in the final survey. In generating the final set of questions, the expert advice received from Picker Institute Europe, the results from the focus groups and the Delphi study were combined to produce a robust survey tool for the Irish context.

2.5 Cognitive interviews

The National Patient Experience Survey team conducted two rounds of cognitive interviews throughout January 2017. In total, 10 individuals took part. Table 2 provides detail on the interviews conducted.

<table>
<thead>
<tr>
<th>Date</th>
<th>Length</th>
<th>Sex</th>
<th>Location</th>
<th>Perspective</th>
<th>Round</th>
</tr>
</thead>
<tbody>
<tr>
<td>12-Jan-17</td>
<td>75 min</td>
<td>Female</td>
<td>Dublin</td>
<td>Relative of patient</td>
<td>1</td>
</tr>
<tr>
<td>13-Jan-17</td>
<td>94 min</td>
<td>Female</td>
<td>Dublin</td>
<td>Patient and relative of patient</td>
<td>1</td>
</tr>
<tr>
<td>20-Jan-17</td>
<td>93 min</td>
<td>Female</td>
<td>Dublin</td>
<td>Patient and Nurse</td>
<td>1</td>
</tr>
<tr>
<td>20-Jan-17</td>
<td>88 min</td>
<td>Male and Female</td>
<td>Dublin</td>
<td>Patient (male) and relative of patient (female)</td>
<td>1</td>
</tr>
<tr>
<td>23-Jan-17</td>
<td>39 min</td>
<td>Female</td>
<td>Galway</td>
<td>Patient and relative of patient</td>
<td>2</td>
</tr>
<tr>
<td>24-Jan-17</td>
<td>85 min</td>
<td>Male</td>
<td>Galway</td>
<td>Patient</td>
<td>2</td>
</tr>
<tr>
<td>26-Jan-17</td>
<td>65 min</td>
<td>Male</td>
<td>Dublin</td>
<td>Patient</td>
<td>2</td>
</tr>
</tbody>
</table>
The purpose of cognitive interviewing, or cognitive testing, is to understand how respondents understand survey questions, to identify and correct problems with the survey tool, and to contribute to the analysis and interpretation of the survey data.\(^{(17, 18)}\) Broadly speaking, cognitive interviews gather information using two methods: think-aloud (where participants verbalise their thought processes) and probing (focused, structured questions where participants explain their responses and or offer their views).\(^{(19)}\)

Cognitive interviews are usually conducted at an earlier stage of the questionnaire development process, and this tends to be followed by a pilot of the survey.\(^{(17)}\) However, piloting of the National Patient Experience Survey questionnaire was not planned since the questions are already internationally validated. Nonetheless, it was important to perform cognitive interviewing to rule out any problems with the new question on health insurance status and other necessary variations on the original questions from the Picker library.\(^{‡}\) Similarly, the cognitive interviews allowed assessment of whether further cultural adaptations were required. The invitation letter was also assessed as part of the cognitive interviews.

The feedback gathered in the cognitive interviews was implemented within the constraints of maintaining international comparability. Following the cognitive interviews, the questionnaire and invitation letter were reviewed by the NPE Survey Programme governance groups\(^{§}\) and the managed service.\(^{**}\) Additional changes suggested by these groups are described in the report on the cognitive interviews. The National Patient Experience Survey steering group approved the final survey design.

---

\(^{‡}\) New questions (not included in the original Picker library of questions) and necessary variations on the original questions are outlined in the report on the consultation meeting with the Picker Institute Europe\(^{(22)}\).

\(^{§}\) The National Patient Experience Survey Programme is governed by a steering group, an advisory group and a delivery group, all of which include representatives from HIQA, the HSE and the Department of Health. The steering group includes members of senior management of the partner organisations. The steering group and the advisory group also include patient representatives.

\(^{**}\) The managed service is a third party organisation, contracted by HIQA that is responsible for the distribution and collation of survey questionnaires.
3. Conclusion

HIQA, the HSE and the Department of Health are committed to improving healthcare quality in Ireland through increased patient engagement. The partners understand that patient experience is a fundamental component of healthcare quality, and as such recognise that Ireland needs to develop a standardised national tool to engage with patients to better understand the care they receive.

In developing the NPE Survey tool, efforts were made to reflect the findings from the focus groups, the Delphi study, the expert advice from Picker Institute Europe and the results from the cognitive interviews in the final questionnaire. The NPE Survey questionnaire thus constitutes the end-product of a robust, evidence-informed process. The survey will provide a rich source of information that will assist all of the partner organisations in working towards improving the quality of patients’ experiences in acute healthcare.
Appendix A — A note on Picker Institute Europe

Picker Institute Europe provides a range of services, including research, surveys, analysis and reporting. The Institute designed and delivered the first national Patient Experience Survey for the National Health Service in England and co-ordinated the largest workforce survey in Europe. Its research has formed the basis of several patient-centred care policies in the United States, the United Kingdom and Australia.\(^{20}\) The Picker Principles of Care\(^{21, 22}\) have been adopted by many countries internationally and as such constitute a renowned quality improvement framework underpinning quality management in healthcare internationally.

The Picker Institute developed eight *Principles of Patient-Centered Care* through many focus groups with recently discharged patients, family members and hospital staff (physician and non-physician) in an effort to understand how care is perceived through the patient’s eyes.\(^{21, 22}\)

References


