



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# **International Review National Patient Experience Survey**

October 2016

# About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent authority established to drive high quality and safe care for people using our health and social care services in Ireland. HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered.

HIQA aims to safeguard people and improve the safety and quality of health and social care services across its full range of functions.

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

**Setting Standards for Health and Social Services:** Developing person-centred standards, based on evidence and best international practice, for health and social care services in Ireland.

**Regulation:** Registering and inspecting designated centres.

**Monitoring Children's Services:** Monitoring and inspecting children's social services.

**Monitoring Healthcare Safety and Quality:** Monitoring the safety and quality of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.

**Health Technology Assessment:** Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.

**Health Information:** Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

## **Overview of Health Information function**

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is therefore imperative that information is managed in the most effective way possible in order to ensure a high quality, safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests – if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has a key role to play in healthcare planning decisions – where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under section (8)(1)(k) of the Health Act 2007, the Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented with major gaps and silos of information which prevents the safe, effective, transfer of information. This results in service users being asked to provide the same information on multiple occasions.

Information can be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and increased cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base our decisions. As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice.

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements. In the area of health information, HIQA has responsibility for evaluating information resources, publishing information about the delivery and performance of health and social care services and using this information to deliver its regulatory functions. To this end, this international review will inform recommendations on a national approach to capturing patient experience for the Irish healthcare sector.

## Table of Contents

|  |    |
|--|----|
| <b>1. Introduction</b> .....   | 1  |
| 1.1 Aims and Objectives .....  | 3  |
| 1.2 Methodology .....  | 3  |
| 1.3 Project Background .....   | 3  |
| 1.3.1 Previous National Survey Models .....                                    | 4  |
| 1.3.2 National Commitment .....  | 4  |
| 1.4 International Review .....   | 5  |
| <b>2. Summary of Findings</b> .....  | 6  |
| <b>3. Scotland</b> .....   | 9  |
| 3.1 Background .....   | 9  |
| 3.2 Objective .....  | 9  |
| 3.3 Commitment .....   | 9  |
| 3.3.1 Partnership Approach .....   | 9  |
| 3.3.2 Resources .....  | 10 |
| 3.3.3 Budget .....   | 10 |
| 3.4 Legislative Requirements for Data Protection .....                         | 10 |
| 3.5 Governance Arrangements .....  | 11 |
| 3.6 Survey .....   | 12 |
| 3.6.1 Survey Sample .....  | 12 |
| 3.6.2 Survey Questions .....   | 12 |
| 3.6.3 Distribution and Collection .....  | 13 |
| 3.6.4 Survey Helpline .....  | 13 |
| 3.6.5 Communication .....  | 13 |
| 3.6.6 Analytical Methodologies and Tools .....                                 | 14 |
| 3.6.7 Outputs .....  | 14 |
| 3.7 Key Recommendations and Lessons Learned from the Scottish Government ..... | 15 |
| <b>4. Denmark</b> .....  | 16 |
| 4.1 Background .....   | 16 |
| 4.2 Objective .....  | 16 |

|                   |  |           |
|-------------------|--|-----------|
| 4.3               | Commitment.....  | 16        |
| 4.3.1             | Partnership Approach.....  | 17        |
| 4.3.2             | Resources .....  | 17        |
| 4.3.3             | Budget.....  | 17        |
| 4.4               | Legislative Requirements for Data Protection.....                                    | 17        |
| 4.5               | Governance Arrangements.....   | 18        |
| 4.6               | Survey .....   | 18        |
| 4.6.1             | Survey Sample .....  | 18        |
| 4.6.2             | Survey Questions.....  | 18        |
| 4.6.3             | Distribution and Collection .....  | 19        |
| 4.6.4             | Survey Helpline.....   | 20        |
| 4.6.5             | Communication .....  | 20        |
| 4.6.6             | Analytical Methodologies and Tools.....  | 20        |
| 4.6.7             | Outputs .....  | 20        |
| 4.7               | Key Recommendations and Lessons Learned from Patient Experience and Evaluation ..... | 21        |
| <b>5. England</b> | .....  | <b>22</b> |
| 5.1               | Background.....  | 22        |
| 5.2               | Objective.....   | 22        |
| 5.3               | Commitment.....  | 22        |
| 5.3.1             | Partnership Approach.....  | 22        |
| 5.3.2             | Resources .....  | 23        |
| 5.3.3             | Budget.....  | 23        |
| 5.4               | Legislative Requirements for Data Protection.....                                    | 23        |
| 5.5               | Governance Arrangements.....   | 24        |
| 5.6               | Survey .....   | 24        |
| 5.6.1             | Survey Sample .....  | 25        |
| 5.6.2             | Survey Questions.....  | 25        |
| 5.6.3             | Distribution and Collection .....  | 26        |
| 5.6.4             | Survey Helpline.....   | 26        |

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|           |   |           |
|-----------|---|-----------|
| 5.6.5     | Communication .....   | 26        |
| 5.6.6     | Analytical Methodologies and Tools.....                       | 27        |
| 5.6.7.    | Outputs .....   | 27        |
| 5.7       | Key Recommendations and Lessons Learned from England .....    | 28        |
| 5.7.1     | Care Quality Commission .....                                 | 28        |
| 5.7.2     | Picker Institute Europe .....                                 | 28        |
| <b>6.</b> | <b>New Zealand .....</b>                                      | <b>29</b> |
| 6.1       | Background.....   | 29        |
| 6.2       | Objective.....  | 29        |
| 6.3       | Commitment.....   | 29        |
| 6.3.1     | Partnership Approach.....                                     | 30        |
| 6.3.2     | Resources .....   | 30        |
| 6.3.3     | Budget.....   | 30        |
| 6.4       | Legislative Requirements for Data Protection.....             | 31        |
| 6.5       | Governance Arrangements.....                                  | 31        |
| 6.6       | Survey .....  | 32        |
| 6.6.1     | Survey Sample .....   | 32        |
| 6.6.2     | Survey Questions.....   | 33        |
| 6.6.3     | Distribution and Collection .....                             | 34        |
| 6.6.4     | Survey Helpline.....  | 35        |
| 6.6.5     | Communication .....   | 35        |
| 6.6.6.    | Analytical Methodologies and Tools .....                      | 35        |
| 6.6.7     | Outputs .....   | 35        |
| 6.7       | Key Recommendations and Lessons Learned from New Zealand..... | 36        |
| <b>7.</b> | <b>Conclusion.....</b>  | <b>37</b> |
| 7.1       | Findings.....   | 38        |
| 7.1.1     | Objective.....  | 38        |
| 7.1.2     | Commitment.....   | 38        |
| 7.1.3     | Legislative Requirements for Data Protection .....            | 38        |
| 7.1.4     | Governance Arrangements.....                                  | 38        |

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|             |   |    |
|-------------|---|----|
| 7.1.5       | Survey .....  | 38 |
| 7.1.6       | Outputs .....   | 39 |
| 7.2         | Next Steps .....  | 39 |
| Appendix 1: | Organisations and participants that contributed to review ..... | 40 |
| Appendix 2: | Surveys conducted by each jurisdiction reviewed .....           | 41 |
| References  | .....   | 42 |



## **1. Introduction**

There is strong evidence showing that significant benefits can be gained from implementing a national patient experience survey. A national patient experience survey provides a voice for patients, facilitating greater engagement by patients in their care.

Implementing a national patient experience survey will drive accountability; identifying where excellent and poorer service are provided, potentially allowing service providers to benchmark the care that they provide both nationally and internationally. The policy developer will have definitive data on the success or otherwise of national policy and planning, and informing the need for additional policies and legislation.

The Health Information and Quality Authority (HIQA) was established under the Health Act 2007 with the primary aim to promote patient safety and quality throughout health and social care in Ireland.<sup>(1)</sup> HIQA has a broad statutory remit, including both regulatory functions; which consists of inspection and monitoring activities; and functions aimed at planning and supporting sustainable improvements.

HIQA's role is to promote quality and safety in the provision of health and personal social services for the benefit of the public's health and welfare. Interest in a national patient experience survey has stemmed from this function as the survey can be used to promote sustainable improvements, safeguard people using health and social care services and support informed decisions on how services are delivered.

A joint partnership programme between HIQA, the Department of Health and the Health Service Executive (HSE), has been established to put in place a plan for the measurement of patient experience across Irish healthcare services.

It is internationally accepted that collecting patient feedback is a necessary factor in determining where patient expectations in healthcare are being met and where they are falling short. A holistic way of capturing this patient feedback is through a national patient experience survey.

Patient satisfaction surveys and patient experience surveys are often referred to interchangeably; however, the model and implementation methodology are quite different. Patient satisfaction can vary as a result of differing patient expectations. For example, patients with similar experiences but different expectations about the

care provided can have varying levels of satisfaction. Patient satisfaction is one factor in the overall patient experience. On the other hand, patient experience is an all encompassing focus on individualising care in order to tailor healthcare services to meet specific patient needs and engage patients as partners in their care.<sup>(2)</sup>

The differences are summarised below:

- Patient satisfaction surveys tend to be conducted during the hospital stay; whereas patient experience surveys are distributed after the patient leaves the hospital, generally within two weeks, in order to avoid the 'halo' effect. The halo effect in this case is where the patient is biased toward giving a positive response as they are very grateful that they are going home.
- The format of the questions can also vary. The patient satisfaction survey can be more general in nature, for example, "was the accommodation clean"; whereas, the patient experience survey focuses on a particular area, for example, "was the hospital room clean."
- Patient satisfaction surveys can be left in different departments throughout the hospital or given upon discharge, and therefore, the sample size and response rates may not be known. The sampling for patient experience surveys is structured and sample sizes and response rates are known.
- Satisfaction surveys are local to the service provider or service provider group allowing local improvements but national comparisons are not possible; whereas, Patient experience surveys are a national survey allowing service providers to benchmark their care and service delivery nationally.

The administration of a national patient experience survey has been found beneficial across the entire healthcare spectrum. The use of patient experience surveys can lead to enhanced patient recovery, improved productivity and efficiency, informed choice by patients, and lower staff turnover and absenteeism.<sup>(3)</sup> The patient experience survey offers a way for patients to be engaged, active, and informed in their own care. For providers, the data collected by the surveys helps to identify areas for improvement, provide assurance in the care being provided, and benchmark patient experience both nationally and internationally. The survey is one tool that informs about the quality and safety of care provided to patients driving accountability across the healthcare services. The survey findings can inform Policy developers about the success or otherwise of national legislation and policy.

MCG Adult Centre for Excellence in Neuroscience in Augusta, Georgia adopted a patient engagement programme. As part of that programme a Patient Experience Survey was introduced. As a result of engaging with patients The Neuroscience Centre has experienced improvement across a broad range of areas. In just three years the neurosurgery length of stay decreased by 50% and the number of patients discharged increased by 15.5% as a result of more efficient delivery of care. The staff vacancy rate decreased from 7.5% to 0% and there was a 62% reduction in medical errors. Overall satisfaction rates have increased from the 10<sup>th</sup> to 95<sup>th</sup> percentile.<sup>(4)</sup> These improvements have a significant positive impact for the patients.

### **1.1 Aims and Objectives**

The aim of this international review is to identify and analyse international experience and best practice with regard to the model and methodology employed to deliver a national patient experience survey. There is currently no nationally standardised, comparable patient experience data being collected within Ireland.

This report therefore identifies how international organisations and agencies are using national patient experience data to support service delivery, quality and safety improvement initiatives, and regulation. Through identifying international best practice, this review is a step towards informing HIQA on the most advantageous approach to implement a national patient experience survey in Ireland.

### **1.2 Methodology**

The jurisdictions reviewed were chosen as a result of a desktop search that identified a range of initiatives that could potentially contribute to informing HIQA's best practice approach when implementing a national patient experience survey. The countries were chosen based on factors identified in the desktop review including the availability of relevant and current information and access to key personnel.

Findings were compiled through national documentation from each country and detailed discussions were held with key personnel from agencies and organisations within each of the jurisdictions. Table 1 (page 40) lists the personnel who were consulted within each organisation.

### **1.3 Project Background**

Currently in Ireland there is no standardised, comparable patient experience surveys applied across the health sector. The Department of Health point out in their *2014 National Healthcare Quality Reporting System* that "if you don't measure it, you cannot improve it".<sup>(5)</sup>

It is international best practice to collect and report on patient experience<sup>(6)</sup>. The purpose of this review is to examine successful patient experience models and methodologies to identify the necessary process to develop and implement a national patient experience survey in Ireland.

### 1.3.1 Previous National Survey Models

The Irish Society for Quality and Safety in Healthcare conducted national patient surveys in 2000, 2002, 2006 and 2010.

The most recent Irish Society for Quality and Safety in Healthcare survey was conducted in partnership with the University of Ulster in 2010, and while both the survey and analysis were robust and reflected best practice, participation by hospitals was voluntary. Consequently, only 25 of 49 hospitals participated, and there was no follow up of quality improvement initiatives that took place as a result of the findings.

### 1.3.2 National Commitment

This review identifies the commitment required from Ireland in terms of resources and information technology; the internal and external governance structures necessary to undertake a national survey process; and the communication and reporting requirements to inform the patients, public, service providers and stakeholders about the actual survey and the findings.

## **1.4 International Review**

The countries that are reviewed in this report are as follows:

- Scotland
- Denmark
- England
- New Zealand

This review identifies the model and methodology used by the above jurisdictions for their national patient experience surveys.

The areas that this review focuses on are:

- Requirements from an operational perspective (that is; model, methodology, resources, governance structures, information governance, administration, development of survey model, capital and information technology).
- Administrative requirements: Communications, Distribution.
- Outputs: What is reported (that is to say; national, regional, department level reports); what happens with the results; how are they followed up with by the service provider, quality improvement agency and regulator.

## **2. Summary of Findings**

The below provides a summarised overview of the findings of this review:

- All international jurisdictions reviewed have been conducting patient experience surveys for a number of years.
- The benefits of national patient experience surveys are significant for all those involved that is the patient, service provider, regulator and policy developer.
- Adopting a partnership model ensures the patient is the priority across the entire health system.
- Strong governance arrangements are required to clearly identify each partners' roles and responsibilities.
- Surveys should be conducted on an annual basis as it provides a richer source of data.
- The scope of the survey should be clear.
- It is not advisable to develop your own survey questions, use internationally recognised questions that allow for comparison of results nationally and internationally, thus enhancing learning.
- The same questions should be used year on year to allow trending and tracking of quality improvements.
- A section of four or five theme based questions can be included and changed annually to allow focus on specific themes.
- Make sure that patients have the ability to include written comments, as this provides a rich source of data for quality improvement.
- The data protection legislation for the jurisdictions examined allows sharing of personal data with third parties if it improves the quality and safety of care for the patient.
- Death checks are extremely important and should be conducted right up to the point that the surveys are distributed.
- Communication must be robust between a variety of stakeholders including patients, healthcare professionals, professional regulatory authorities and the public.

- The implementation of a national patient experience survey requires significant capital, resource and administrative commitment but as commented by the Care Quality Commission 'it is absolutely worth doing'.

**Model and methodology  
applied  
to implement  
National Patient  
Experience Surveys**



### **3. Scotland**

Scotland has a population of 5.3 million.<sup>(7)</sup>

#### **3.1 Background**

Scotland's first national patient experience survey was conducted in early 2010 as a national acute sector inpatient survey. The Scottish Care Experience Programme now conducts a suite of national patient experience surveys, including the following:

- Inpatient Experience Survey
- Health and Care Experience Survey (General Practitioner (GP) Services)
- Maternity Care Experience Survey

#### **3.2 Objective**

The survey programme is conducted to provide a basis for measuring the quality of healthcare as experienced by patients. The programme supports the three quality ambitions of the Healthcare Quality Strategy for NHSScotland: safe, effective, and person-centred care.<sup>(8)</sup>

The surveys aim to provide GP Practices, local authorities, National Health Service (NHS) hospitals and Boards with feedback on their patients' experiences. This data is used for local improvement, providing feedback on the experiences of patients relative to previous surveys. It also demonstrates variation between and within NHS Boards. Nationally, the results are used to identify variations between local areas, highlight areas of best practice as well as areas for improvement, explore the variations in the experiences of different groups of patients, and informing a range of national policies.

#### **3.3 Commitment**

A significant level of commitment is required across the Healthcare Sector in order to successfully implement a national patient experience survey.

##### **3.3.1 Partnership Approach**

The Scottish Care Experience program is jointly managed through a partnership between:

- The Scottish Government
- NHSScotland: Information Services Division.

The Scottish Care Experience Programme is managed and conducted by The Scottish Government. The Government works closely with the Information Services Division to ensure that the survey data is analysed to produce NHS Board and hospital level

reports that the Government then publishes. NHSScotland consists of 14 regional NHS Boards responsible for protecting and improving the population's health and the delivery of leading healthcare services.<sup>(9)</sup> There are additional Special NHS Boards who support the regional NHS Boards by providing a range of specialist and national services. Healthcare Improvement Scotland provides support to the NHS Boards to use the survey results to improve healthcare services

### 3.3.2 Resources

Scotland requires a team of five who collaborate with an approved survey contractor responsible for administering the patient experience survey.

This team consists of:

- three members of the Scottish Government
- two members in the Information Services Division (Part of NHS National Services Scotland).

### 3.3.3 Budget

Scotland spends a majority of its survey budget on the approved survey contractors who administer the Patient Experience surveys.

- The GP Survey, now called the Scottish Health and Care Experience Survey, costs €650,000, involves 600,000 patients and 1,000 GP Practices
- The Inpatient Survey costs €91,000, covers 45,000 patients and 60 hospitals
- The Maternity Survey costs €26,000, covers 5,000 patients (10% of annual births).

## 3.4 Legislative Requirements for Data Protection

Personal data is required in order to conduct the process of a national patient experience survey. While Scotland gives significant consideration to protecting personal data, they are allowed to give an approved survey contractor access to personal data in accordance with the NHS ethical approval for the survey. All personnel with access to personal data are governed by the NHS Research Governance Framework for Health and Community Care.

Both the Information Services Division and the approved contractor work together to ensure that all data is securely transferred via secure File Transfer Protocol with secure login. Files are immediately deleted from the system once they are received by the contractor. The minimum requirements to be adhered to regarding ethics, data transfer and data security for fieldwork are set out in the survey guidance manual.<sup>(9)</sup>

Scotland is also required to uphold the principles outlined within the Data Protection Act 1998. The first principle of the Data Protection Act calls for the processing of all personal data to be “fair and lawful”.<sup>(10)</sup> Specifically, reasonable steps must be taken to inform the public about the purposes for which their personal information may be used and to whom this information will be disclosed. This can be done through pre-survey publicity such as informational leaflets or posters. Any information written within the free text comments that could be considered personal by respondents, other patients, or staff must also be removed as part of compliance with the Data Protection Act.<sup>(9)</sup>

### **3.5 Governance Arrangements**

The Chief Nursing Director at the Scottish Government is the co-ordinator of the patient experience survey at a national level. Each Board also has a Patient Experience Lead; this person conducts sampling at the local level.

Scotland first used steering groups to advise on the design of the questionnaire and to agree on the scope of the survey. These groups are not always necessary, depending on the scale of review, but experts in specific areas are sought out to consult on the design, redesign, or results of a survey.

Healthcare Improvement Scotland intend to look at patient experience data in a more proactive way as they develop quality of care reviews. There are a number of questions in the national patient experience survey that Healthcare Improvement Scotland plan to focus on to inform their risk assessments. They have commissioned work to understand patient experience in greater detail, through focus groups and other mechanisms that engage with patients, carers and families locally.

## **3.6 Survey**

In terms of the survey itself, the sample size, questions, distribution and collection, communication, analytical methodologies, tools and survey outputs need to be considered.

### **3.6.1 Survey Sample**

It is important to have an adequate sample size to validate the results of the survey. The sampling approach for the Scottish Inpatient Patient Experience Survey was agreed with each NHS Board to meet their needs in providing results locally. These strata were defined either at site (hospital) level, sub-site (directorate or grouped specialties) level or as groupings of smaller hospitals. This amounts to a total of approximately 45,000 patients required for inclusion in the survey. The sample is randomly selected and includes adult patients, aged 16 years old and above on discharge, who had an NHS inpatient hospital stay. The most recent inpatient survey selected patients from a six month sampling period.

The survey sample is selected from a centralised NHS Information Services Division database that holds all of the discharge records. The names and addresses of the patients selected are sent to an approved survey contractor in order to distribute the national survey packs.

The response rate from the sample is 50%.

### **3.6.2 Survey Questions**

The national surveys are completed every two years to include enough time for improvements to be put in place. Each questionnaire contains 80 questions. Questionnaires are reviewed periodically to ensure that they remain relevant, whilst still retaining some consistency to allow for comparisons of responses over time.

The current Inpatient Patient Experience Survey includes questions regarding patients' experiences of:

- admission to hospital,
- the hospital and ward environment,
- care and treatment including errors,
- operations, hospital staff, arrangements for leaving hospital, and care and support services after leaving hospital,
- person centred care,
- and, patient Safety.<sup>(8)</sup>

### 3.6.3 Distribution and Collection

Scotland uses approved survey contractors to distribute the patient experience survey packs. Contractors are appointed through a Framework Agreement, which was developed after a rigorous selection process run by NSS National Procurement responsible for national procurement exercises for the NHS in Scotland.

The surveys are distributed via post. Online surveys are also offered, but they do not have a very high response rate. Postal survey packs are printed by the contractor and administered to hospitals on behalf of each NHS Board.

The pack contains:

- introductory cover letter,
- patient Survey,
- a language sheet,
- information leaflet,
- and, FREEPOST envelope to return survey.

A reminder letter is posted two weeks after the initial pack is sent. After an additional two weeks, a second and final reminder letter is sent along with an additional survey pack. Posting a second reminder pack has been found to generate a higher response rate for the national patient survey.

Completed surveys are returned to the approved survey contractor to be anonymised and transferred to NHS Information Services Division for data analysis. The completed questionnaire is first separated from the patient name and address and is then linked to a unique ID number to maintain anonymity.

### 3.6.4 Survey Helpline

Any surveyed patients with language and sight difficulties have the option of calling a helpline service to complete their survey. The patient will enter their unique ID code online to maintain anonymity. A translation service is also available; however its use is very low.

### 3.6.5 Communication

The survey pack contains both a cover letter and information leaflet to communicate the importance of the survey to participants. The cover letter describes why the participants were selected to complete the survey, information regarding data protection, and instructions on how to complete the questionnaire.

The information leaflet explains the arrangements for reporting the survey results and includes directions for accessing the survey in other formats, such as the

translation helpline. Participants who do not wish to take part in the survey are advised to indicate this either by phoning the helpline number and leaving their details to be removed from the mailing list or returning the uncompleted questionnaire using the FREEPOST envelope.<sup>(9)</sup>

### 3.6.6 Analytical Methodologies and Tools

The data collected is analysed to find indications of variances in patient experiences and care quality to initiate improvements. The data analysis and reporting is conducted by NHS's Information Services Division. The survey data collected by the approved survey contractor is securely transferred to Information Services Division via secure File Transfer Protocol. The data is then analysed using the statistical software package SPSS. The Scottish Government uses SAS Business Intelligence software to interrogate and store the large datasets. They are working towards archiving data in a warehouse, potentially in a university to better allow the data to be used for research purposes.

The NHS Boards are not weighted equally in order to provide more representative results. If NHS boards were given equal weight, the reports would provide misleading results as NHS Boards who see over 80,000 inpatients annually would have the same weight as those who see fewer than 1,000 inpatients annually. The effect of this would lead to inflated results as smaller boards typically achieve higher positive scores. Historically Scotland has weighted the results on patient experience surveys, and continuing to use this methodology allows for consistent comparison of results over time.

### 3.6.7 Outputs

Following analysis, the information produced by Information Services Division is transferred to the Scottish Government for report writing. The national patient experience response data is generated into both a national report and more detailed Hospital/NHS Boards reports. The data, including patients' comments, is then provided to the regulator, Health Improvement Scotland and service providers to investigate individual issues. This was found to be extremely helpful for continued quality improvement purposes.

The Hospital/NHS Boards reports do not translate to a department or specialty level. If a hospital or NHS Board requires more detailed information, they are encouraged to conduct their own patient experience survey once the national survey is published. These additional surveys can be used by hospitals to drill down into more detail and understand what is happening within their own area.

### **3.7 Key Recommendations and Lessons Learned from the Scottish Government**

The following are key recommendations and lessons learned:

- In Scotland the original survey questions were tailored to specific policy or operational priorities, however, this involved a significant workload to develop and cognitively test each question. For this reason, Scotland now uses questions from existing questionnaires as a starting point when developing new surveys, allowing use of questions that are readily available, tried, and tested. In addition, this facilitates international comparisons.
- Having checks in place to ensure that questionnaires are not sent to deceased patients are extremely important; continue to do this right up to the day that the questionnaire is sent out.
- Resources were saved as a result of adopting a centralised approach. The inpatient survey moved from a NHS Board-led model to a centralised approach.
- While it is important to have a national central approach it is vital to provide timely meaningful data at a local level.

## **4. Denmark**

Denmark has a population of 5.6 million.<sup>(11)</sup>

### **4.1 Background**

In Denmark, the healthcare sector is divided into five regions; Capital Region of Denmark, Region Zealand, Region of Southern Denmark, Central Denmark Region, and North Denmark Region. The National Danish Survey of Patient Experiences (LUP) is conducted under an agreement between the Danish government and Danish Regions.

Denmark's first survey of patient experiences was conducted in 2000. Initially, the survey was conducted every two years, but it has been carried out as an annual nationwide survey since 2009 in order that the results are more representative of changes that occur annually. The results from the survey identify areas for improvement at a national, regional, hospital, and unit level.

The LUP is currently used to capture the experiences of:

- acute inpatients
- elective (planned) inpatients
- outpatients
- maternity care
- and, outpatients in emergency wards.

### **4.2 Objective**

Denmark uses national patient surveys not only to identify focus areas for improvement, but also to:

- identify the effects of previous initiatives
- compare patients' experiences across hospitals and departments
- focus on specific themes
- focus on specific users and patient groups.<sup>(12)</sup>

### **4.3 Commitment**

A significant level of commitment is required across the Healthcare Sector in order to successfully implement a national patient experience survey.



### 4.3.1 Partnership Approach

The National Danish Survey of Patient Experiences is conducted under an agreement between:

- The Ministry of Health and Prevention (a part of the Danish Government)
- The Danish Regions

The Danish Regions have hired an approved survey contractor, the Centre for Patient Experience and Evaluation Denmark, to facilitate and administer the National Danish Survey of Patient Experiences (LUP) on behalf of the Danish Regions and The Ministry of Health and Prevention. The Centre for Patient Experience and Evaluation is a research centre working to promote patient and user experienced quality in healthcare.<sup>(13)</sup>

### 4.3.2 Resources

Denmark requires a team of four or five to work on the LUP. An additional four or five employees are added to the team when needed to assist in analysing results and writing the national report.

### 4.3.3 Budget

Denmark has an overall budget for the LUP of 8 million Dkr (approximately €1 million). The patient experiences survey is entirely financed by the five Danish Regions that are responsible for managing Denmark's hospitals.

50% of the budget goes to an approved Danish survey contractor. The contractor's role includes postal, printing, and scanning expenses. The remaining 50% is used to pay the salaries of personnel in the Centre for Patient Experience and Evaluation who are responsible for the ongoing development of the survey, for example, designing new questions and validation of the questionnaire, preparation of the test sample, and the analysis of data and writing of reports.

## 4.4 Legislative Requirements for Data Protection

Denmark is legally permitted to access identifiable data if it is necessary for performing a task carried out in the public interest. However, they are required by the Processing of Personal Data Act (2000) to have security agreements in place with any external contractors to ensure that all data is kept confidential and secure. The Processing of Personal Data Act requires that any public research project using personal data be authorised by the Danish Data Protection Agency before the public authority may begin work on the project. Any public research projects at hospitals

must be reported via the Regions. Hospitals cannot submit a notification directly to the Danish Data Protection Agency.<sup>(14)</sup>

To keep personal data anonymous in the survey and the analysis, each patient is assigned a patient number matched on their questionnaire. There are only three employees that have the ability to connect the assigned patient number with the patient specific data if necessary.

#### **4.5 Governance Arrangements**

Denmark's national patient experience survey is conducted by the Centre for Patient Experience and Evaluation on behalf of the Danish Regions, who are responsible for the hospitals. A steering group is in place to manage the overall survey. This group consists of representatives from the Danish Regions and the Ministry of Interior and Health.

#### **4.6 Survey**

In terms of the survey itself, the sample size, questions, distribution and collection, communication, analytical methodologies, tools and survey outputs need to be considered.

The below outlines what Denmark has in place in this area:

##### **4.6.1 Survey Sample**

It is important to have an adequate sample size to validate the results of the survey. Denmark has used the same sample size since conducting their first survey in 2000. Surveys are sent to approximately 230,000 patients, or 400 patients per unit within each hospital. Units must have a minimum of 30 patients to be included (with questionnaires sent out), and at least 20 patients must answer to be included in the final results. If a unit has less than 400 patients in the sample period all the patients are included. Denmark has a response rate of approximately 50-55%.

The questionnaires are sent out centrally to a sample that is selected over a three month sample period for inpatients and a one and a half month period for outpatients. The sample is selected from the National Patient Registry, which holds necessary information about every contact between Danish citizens and the hospital services. An outpatient is defined as having had at least one hospital visit during the sample period. An inpatient is defined as having had a minimum of 24 hours of hospitalisation during the sample period.<sup>(13)</sup>

##### **4.6.2 Survey Questions**

Denmark developed an original set of questions for the LUP. This requires intensive consultation and collaboration with a broad group of stakeholders including:

patients, healthcare professionals, and professional regulatory authorities. Once the stakeholders finish deliberating on a set of questions, a validation process commences where 140 patients in individual interviews review the questions in detail. Representatives from each region provide the final approval on questions.

The LUP contains about 40-45 questions. The questionnaires are general in nature to allow for comparability despite patient's disease and treatments.

The questions focus on topics including:

- information about waiting time
- contacts and co-ordination of care
- patient and relative co-involvement
- patient experiences of error
- information
- discharge (inpatients only)
- intersectoral collaboration
- overall impression of hospital visit.<sup>(13)</sup>

#### 4.6.3 Distribution and Collection

The Regions have hired an approved survey contractor to distribute their survey via post. However, survey participants are also able to log into the website specified in the survey pack and answer the questions electronically if they prefer. There is a movement in the Danish public to communicate solely electronically with patients so Denmark hopes to only send questionnaires electronically in the future.

An approved Danish survey contractor is responsible for printing and distributing the survey packs. The packs are distributed at three different timeframes throughout the sample period to allow for their receipt to be as close as possible to the patient's discharge date. A reminder letter is posted two weeks after the initial pack is sent. A questionnaire is included with the reminder letter.

From November 1<sup>st</sup> 2014 every Danish citizen above the age of 15 is issued an electronic mailbox to receive Digital Post from public authorities.<sup>(15)</sup> Digital Post can be accessed on two secure websites using a digital signature to ensure security. In 2015 the Centre for Patient Experience and Evaluation distributed the surveys to the survey participants' electronic mailboxes via Digital Post and 40% of survey responses received was submitted using this method. Sending the surveys electronically is a significantly less expensive method than through post, so it is hoped that the questionnaire will only be distributed with this method once the public becomes comfortable responding to surveys electronically.

#### 4.6.4 Survey Helpline

The national survey does not accommodate non-Danish speakers. At this time English speakers may have the questionnaire translated, but this doesn't occur often. Producing an English translation of the survey pack has been considered, however other languages have not been considered at this time.

#### 4.6.5 Communication

Denmark values communication with the patient throughout the duration of the National Danish Survey of Patient Experiences. Significant input from patients was taken into consideration when developing the survey question set. Consensus groups with patients were used to decide on the questions. Draft questionnaires were administered to patient groups, and patients in focus groups discussed their understanding of the questions and layout of questionnaire. A cover letter is included in the survey pack to further explain the importance of completing the national survey.

#### 4.6.6 Analytical Methodologies and Tools

The survey response data is transferred from the contractor to the Centre for Patient Experience and Evaluation using File Transfer Protocol. The data is scanned and pulled directly into the statistical system, SAS, for the Centre for Patient Experience and Evaluation to interrogate the data.

#### 4.6.7 Outputs

Survey results are reported at unit, hospital, regional, and national levels. The primary target group for results is the hospital unit as they have the direct patient contact to better initiate improvements in care provided. Written comments are fed back to each unit in order to give individual teams a sense of what is most important for the patient.

Each region can decide how they want to use the results within their hospitals:

- contracts can be made with hospitals to require improvements
- contracts can be combined with payment
- units can be required to follow-up on the results leaving a range of improvement initiatives.

The aim of conducting continuous measurements is to ensure that the improvement of patient experience is an ongoing process with the following components:

- receipt of own (unit) results
- assessment of results
- identification of areas of improvement and preparation of plan of action
- implementation of improvement initiatives
- a new LUP measurement reflecting the progress since the last survey.

This process uses benchmarking as an indication of whether a result has changed in a positive or a negative way since the last survey. This provides hospitals and units with a basis for evaluating and acting upon their results.

#### **4.7 Key Recommendations and Lessons Learned from Patient Experience and Evaluation**

The following are key recommendations and lessons learned from the Danish survey:

- The patient needs to be the focus. It is essential that their experience is captured.
- Bring healthcare professionals into the process from the outset; ensuring they find the surveys meaningful allows healthcare providers to improve and accept results.
- Make sure that patients have the ability to include written comments in the questionnaire.
- In order to make the results easier and of greater value for specialities or units, try to focus questions and patient groups accordingly.
- Ensure questions are not too general, as this makes it difficult to follow up afterward.
- Decide if the national patient survey is a tool for improvement or a tool for regulation.

## **5. England**

England has a population of 53 million.<sup>(7)</sup>

### **5.1 Background**

England's National NHS Patient Survey Programme currently carries out the following surveys:

- National Children's Inpatient and Day Case Survey
- Inpatient Survey (Annually)
- Community Mental Health Survey
- Maternity Survey (Annually)

The first National Inpatient Survey was conducted in 2002. The latest inpatient survey drew participants from a sample period between June and August 2014. This was the 12<sup>th</sup> survey of adult inpatients conducted in England, and it involved 154 acute and specialist NHS Trusts.<sup>(16)</sup>

### **5.2 Objective**

The purpose of the national survey is to provide Trusts with targeted quality improvement information. The survey results are used for assessing the performance of Trusts and for regulatory purposes.

### **5.3 Commitment**

A significant level of commitment is required across the Healthcare Sector in order to successfully implement a national patient experience survey.

#### **5.3.1 Partnership Approach**

England's National NHS Patient Survey Programme is managed through a co-ordinated approach between:

- The Department of Health
- NHS England
- Care Quality Commission

The Department of Health established the survey programme and partially funds the Care Quality Commission to administer the surveys. The Care Quality Commission provides oversight and guidance to the Picker Institute Europe. NHS England uses the findings from the patient experience survey in the NHS Outcome Framework.

### 5.3.2 Resources

The Health Intelligence Unit, a division of the Care Quality Commission, manages the patient experience survey. The team responsible for the patient experience survey currently has four staff members; however, they are in the process of expanding this to six staff members. Either the individual Trust or an approved survey contractor is responsible for conducting the sampling for the surveys.

### 5.3.3 Budget

England budgets approximately €4 million for the national patient experience survey. This cost covers an entire suite of surveys over three years. In order to participate in the national patient experience survey, each Trust must pay €5,200.

Care Quality Commission contracts Picker Institute Europe to develop guidelines, develop and manage the website, manage communication with service providers and subcontractors, analyse and report the results. The Picker Institute usually requires four staff members per survey. Currently, Trusts have the option of using mailing sub-contractors to conduct the fieldwork, and the Picker Institute's is also one of the approved mailing sub-contractors for some Trusts.

## 5.4 Legislative Requirements for Data Protection

Under the Health and Social Care Act, section 25(1), patient identifiable information is legally allowed to be transferred to a third party for the purpose of research. England has established thorough guidelines to ensure that personal data remains secure and confidential.

Trusts are required to comply with the following legislation:

- Data Protection Act 1998
- NHS Code of Practice on Confidentiality
- Caldicott principles

Trusts sign declarations of compliance to ensure that all precautions are taken to protect personal data. In order for sampling to be conducted by the Trust, the designated person responsible for supervising access to personal information (Caldicott Guardian) must co-sign the Trust's declaration of compliance. If any Trust's Caldicott Guardian does not authorise the declaration of compliance, then sampling is to be done by an approved survey contractor.<sup>(17)</sup>

Approved survey contractors will also work with Trusts to anonymise personal data before the information is sent to the third party contractor working with the Care Quality Commission. To be approved to undertake a national survey on behalf of a

Trust, potential survey contractors must submit their procedures and policies to be reviewed by the Health Research Authority Confidentiality Advisory Group as part of the recommendation for support granted under Section 251 of the NHS Act 2006<sup>(18)</sup>. This ensures that the survey contractor has measures in place to protect the security and confidentiality of data during all stages of the survey.

The Health Research Authority Confidential Advisory Group has been developed to ensure that personal data remains confidential for the entire survey process. Throughout the process, any breach of the data protection act is elevated by the Care Quality Commission in their intelligent monitoring system, usually resulting in an inspection.

Trusts are required under the Data Protection Act 1998 to inform patients about the use of their personal data.<sup>(10)</sup> The Care Quality Commission is legally required by the confidentiality rule to provide the public with the information necessary to make an informed decision to opt out of participating in the national survey. This is done through pre-survey publicity including informational leaflets, brochures, and posters.

## **5.5 Governance Arrangements**

The Care Quality Commission, NHS England and the Department of Health work together to implement England's National Patient Survey Programme. They contract the Picker Institute Europe to develop the survey questionnaires, materials, and methodology for implementing the national surveys. The Care Quality Commission manages the relationship with the Picker Institute.

Care Quality Commission's intelligence unit comprise of:

- The Head of Surveys and Qualitative Intelligence, *reports to the Director of intelligence*
- User Voice Development Manager
- One Analyst Team Leader
- Three Research and survey officers

The Care Quality Commission has monthly meetings with NHS England's Department of Health and the Citizen voice to agree on the strategic development and delivery of the survey programme across health and social care.

## **5.6 Survey**

In terms of the survey itself, the sample size, questions, distribution and collection, communication, analytical methodologies, tools and survey outputs need to be considered.



The below outlines what England has in place in this area:

### 5.6.1 Survey Sample

England's inpatient survey sample is selected by the Trusts. Trusts draw a consecutive sample of patients from a specific sample period of three months. Currently, each Trust selects 850 participants for the inpatient survey. This number is expanding to 1,250 participants in future surveys. Participants must be aged 16 or older with at least one overnight hospital stay during the sample period. Exclusions include maternity or psychiatric patients, patients admitted for planned termination of pregnancy, day case patients, and private (non-NHS) patients. As there are 160 Trusts, this equates to a total of 136,000 participants, moving to 200,000.

Trusts are given the option to administer the surveys to their patients themselves; however, they are strongly recommended to employ the services of an approved survey contractor. Currently over 90% of Trusts use a survey contractor.<sup>(3)</sup> Trusts using an approved contractor send the names and addresses of selected participants to the contractor to distribute and collect their patient surveys.

The response rate of England's latest National Inpatient Survey was 47%.

### 5.6.2 Survey Questions

England keeps the number of questions on their inpatient survey below 60 to reduce the phenomenon of feedback fatigue. They are currently using questions designed and developed by the Picker Institute Europe. The Picker Institute Europe has a library containing a multitude of questions available for selection by clients. England encourages Trusts to develop their own individual surveys to allow for more detail and customisation, but they must use questions from Care Quality Commission's list of pre-approved questions. Using questions from the Picker Institute Europe ensures the validity of the questions and facilitates international comparison of results.

Not all questions are meant to be answered by all respondents. For example, questions regarding operations are only applicable to specific respondents. Survey questions are reviewed annually to keep questionnaires relevant and determine if new questions are needed. However, when possible, the same survey questions are used every year to allow for comparisons. The most recent NHS Inpatient Survey added a statement informing participants that the free text comments will be shared without being anonymised before submission to the Care Quality Commission.<sup>(18)</sup> Free text comments are a rich source of information for Trusts, and this will enable Trusts to review and understand their patients' feedback.

### 5.6.3 Distribution and Collection

England distributes their national patient survey via post as the cohort of patients generally selected to participate in the Inpatient Survey are not comfortable with completing their survey online. Each NHS Trust is responsible for data collection, and an approved survey contractor then distributes the survey pack.

The four approved inpatient survey contractors are:

- Patient Perspective
- Capita Surveys and Research
- Picker Institute Europe
- Quality Health Ltd.

Many approved contractors employ sub-contractors to carry out the mailing of the survey packs. The survey packs distributed by contractors consist of:

- covering letter
- questionnaire
- multi-language sheet
- Freepost return envelope.

To increase response rates, a reminder letter is posted to survey participants two weeks after the initial survey pack. A second and final survey pack is posted to participants an additional two weeks after the reminder letter in an attempt to further increase the response rate.

### 5.6.4 Survey Helpline

England contends that it is important to reach ethnic minority groups in order to obtain results that are representative of all patients. To facilitate this need, England provides a multi-language sheet in the first and third mailings of the survey pack with instructions in the 20 most common non-English languages on how to complete the patient survey by phoning a free helpline to speak with an interpreter.<sup>(18)</sup>

### 5.6.5 Communication

Communication with stakeholders and survey participants is of high importance for the national patient experience survey. The Care Quality Commission composes a letter to be included in patients' discharge packs providing information about the upcoming survey. Two websites are provided for survey guidance, timetables, forms and national tables. A cover letter is included in the survey pack with information about why the survey is being conducted and the importance of patient response.

In addition to survey participants, stakeholders must also be communicated with throughout the entire survey process. The Care Quality Commission has monthly meetings with the Insight Team at NHS England. The Insight team is focused on

gathering patient feedback and using it to improve services. In addition the Care Quality Commission meets the Insight Team within the Department of Health, the NHS England, and the Citizen Voice on a regular basis. The purpose of these meetings is to discuss the progress of each national survey and the strategic direction and delivery of the programme.

#### 5.6.6 Analytical Methodologies and Tools

All survey responses are analysed by the Picker Institute Europe at both a local and national level. Both the Care Quality Commission and Picker Institute Europe use SPSS for analysis. The Care Quality Commission has a scanner that can operate high volumes in seconds. The scanners are used to enter survey details and reduce the potential for human error. The Picker Institute Europe uses SPSS analysis to produce a broad range of reports. Weights are applied to data to give Trusts equal influence over England's national averages. This is done because some Trusts have higher response rates than others.

#### 5.6.7. Outputs

Following analysis, the results are collated into reports by the Picker Institute Europe. The Picker Institute Europe generates a national report and 160 local Trust benchmark reports.

The survey results are then used to inform the work of the Department of Health, NHS England and Care Quality Commission. NHS England uses the results to produce the overall patient experience score, which is updated beside the publication of each national survey. The Department of Health uses results to develop key indicators that support the NHS Outcomes Framework. The Care Quality Commission displays survey data on the organisation search tool to be viewed by the public. The data aims to present each Trust's survey results in a simple and fair manner that allows for nationwide comparison between Trusts. The tool informs as to whether any particular Trust's scores are "better" or "worse" than expected or show any significant changes as compared to the previous surveys.<sup>(19)</sup>

## **5.7 Key Recommendations and Lessons Learned from England**

The following are key recommendations and lessons learned:

### **5.7.1 Care Quality Commission**

- A national patient experience survey is not the easiest of things to do, but it is absolutely worth doing.
- Be clear on what the data is being used for.

### **5.7.2 Picker Institute Europe**

- Make sure governance arrangements and guidance are clearly laid out to ensure confidentiality.
- It is important to be clear what to expect to achieve for different audiences instead of attempting to cover everything at once.
- The scope and content of the questionnaire is of utmost importance. If the questionnaire is too detailed the target audience will not respond to every question; however, if it is at too high level the questionnaire will not inform hospitals or departments with the level of detail they want.
- The raw data is very useful in order to promote the use of information.
- The text section usually provides a rich source of data for quality improvement.
- Using a population based model to capture patient experience is not recommended as it does not accurately reflect patient experience for example a patient that never used hospital services may be included in the response.
- A regulator looks at data in a different way than a service provider.

## **6. New Zealand**

New Zealand has a population of 4.5 million.<sup>(20)</sup>

### **6.1 Background**

In 2000, the Ministry of Health published the Patient Satisfaction Survey Guidelines. A mandatory national inpatient survey was conducted using these guidelines until 2011. The survey ceased when the national quality and risk managers group reviewed the requirements to survey inpatients and found that the reliability and validity of the survey reporting system was “very limited”. It was recommended that the requirement be withdrawn, and while the District Health Boards were incentivised to collect their own patient experience data, there was no consistent national data source to measure the patient experience.<sup>(21)</sup>

New Zealand’s current national patient experience survey was initiated when it was realised that the absence of patient experience data left a gap in the Health Quality and Safety Commission’s national quality and safety indicator set and in the Ministry of Health’s accountability metrics. To address this growing need, the Commission and the Ministry of Health started the process of developing a new patient experience survey in 2013. The 20 question survey focuses on receiving feedback from acute adult inpatients. The first national survey was administered in August 2014 in all 20 District Health Boards, and is now being conducted consistently in hospitals on a quarterly basis.<sup>(21)</sup>

In December 2014, the Ministry of Health and the Commission commenced the process of developing patient experience measures for primary care. It is intended that these will be used in a national online survey for primary care. This survey aims to receive feedback on how patients experience primary care and how overall care is managed between patients’ primary service providers, diagnostic services, specialists and hospital staff.<sup>(22)</sup>

### **6.2 Objective**

The Commission and The Ministry of Health aim to use the data collected by the survey to indicate how healthcare services are performing nationally and to make the care more responsive to improvement. New Zealand has developed the national inpatient survey to be consistent with international best practice and to allow the data to be compared internationally.

### **6.3 Commitment**

A significant level of commitment is required across the healthcare sector in order to successfully implement a national patient experience survey.

### 6.3.1 Partnership Approach

The Patient Experience Programme has a partnership approach between:

- The Ministry of Health
- Health Quality and Safety Commission (the Commission)

The survey programme is led by the Commission and jointly managed with the Ministry of Health. The team responsible for overseeing the national survey programme contains representatives from the Commission, the Ministry of Health policy team, and the National Health Boards.

### 6.3.2 Resources

The key contacts for the patient experience project at the Commission include a Director of Health Quality Evaluation, a Programme Manager, a Principal Advisor of Quality Improvement, and a senior analyst.<sup>(25)</sup>

The Commission contracts Cemplicity as the national survey and reporting system provider. Cemplicity completed the implementation of the final survey, including the following;<sup>(26)</sup>

- online survey tool, including agreed adaptation for each District Health Boards (for example, additional questions, branding)
- the electronic invitation process (email and SMS)
- the paper survey file content and process provided to each District Health Boards so they can print and mail out paper surveys and data enter responses received.

### 6.3.3 Budget

New Zealand has a budget for an approved survey contractor of \$250,000 (approximately €153,500) per year for an estimated contract term of three years. This cost is paid to the national survey and reporting system provider, Cemplicity, to deliver the inpatient experience programme across all New Zealand public hospitals.<sup>(23)</sup>

The cost to implement the technology solution required to test the ability to capture patient experience data into an online process cost the Commission \$38,180 (approximately €23,500).<sup>(24)</sup>

- online reporting and export processes, including accessibility through various browsers used by each District Health Boards
- patient contact alert email
- actions register (where applicable).

## **6.4 Legislative Requirements for Data Protection**

Personal data is required in order to conduct the process of a national patient experience survey. The New Zealand Privacy Act (1993) controls how the survey data is collected, used and stored.

The Privacy Act contains 12 information privacy principles with protocols for the following:

- collection of personal information,
- storage and security of personal information,
- requests for access to and correction of personal information,
- accuracy of personal information,
- retention of personal information,
- use and disclosure of personal information,
- using unique identifiers.

The Privacy Commissioner is responsible for ensuring these principles are followed.<sup>(27)</sup>

To ensure that participants remain confidential, all responses are anonymised unless participants choose to provide their contact details. To keep all information anonymous, each participant imported to the national provider's data warehouse is assigned a unique identification number. The national system provider in charge of distributing the survey invitations is required to host the database containing patient information within New Zealand, and there are strict privacy and security protocols in place that they are required to follow. After the survey has been distributed and the survey link has expired, all patient identifiable information is deleted from the system.

It is important for the District Health Boards that patients be informed of how their information is being used. The general privacy statements already in place in the hospital registration and on admission forms should state that patient information can be provided to other agencies for quality improvement purposes. The District Health Boards will also use public notices and brochures to distribute details about the use of patient information for monitoring quality.<sup>(21)</sup>

## **6.5 Governance Arrangements**

The current patient experience survey programme is overseen by a task and finish group made up of representatives from the Commission, the Ministry of Health policy team, and the National Health Boards. Together, this team works to ensure the efficient implementation of the national inpatient survey.

The task and finish group is responsible for:

- selecting and defining the key indicators,
- designing and testing the survey for use in District Health Boards,
- testing the implementation of the survey to confirm that it captures desired criteria,
- developing the implementation methodology and procedures,
- procuring and implementing the national survey and reporting system,
- supporting District Health Boards on the survey requirements.

The District Health Boards operating policy framework ensures that all District Health Boards must participate in projects led by the Ministry of Health and the Commission. In addition, the Minister's letters of expectation state that the implementation of a national patient experience survey should be a priority for the District Health Boards and the Commission. It is mandatory for all District Health Boards to participate in a minimum of the quarterly national surveys beginning in 2014. District Health Boards may conduct additional surveys if they choose.<sup>(21)</sup>

## **6.6 Survey**

In terms of the survey itself, the sample size, questions, distribution and collection, communication, analytical methodologies and tools and survey outputs need to be considered.

The below outlines what New Zealand has in place in this area:

### **6.6.1 Survey Sample**

New Zealand requires an adequate sample size be selected for the results to better represent the needs of the population. For the national inpatient survey, the Commission recommends a random sample of 400 inpatients be selected from each of the 20 District Health Boards if they admit that many patients during the sample period. This results in a national survey sample of approximately 6,000 patients.

The national inpatient survey is administered on a quarterly basis with a sample period of two weeks. The number of four surveys per year was selected to allow District Health Boards to constantly collect patient feedback to monitor changes and efficiently manage quality improvement. Care is taken to ensure that public holidays are avoided during the selected sample period.

In order to qualify for the survey, participants must be over the age of 15 and have had at least one night's stay in the hospital during the sample period. Exclusions



include patients admitted to a mental health specialty, admitted to another health facility or who died in hospital.

While a completely random survey sample is preferred, partiality is given to those patients with an email address on file to ensure as many online responses as possible. This is followed by a random selection of patients with a mobile number or postal address on file.

The most recent New Zealand national inpatient survey had a response rate of approximately 27%. The Commission hopes for this rate to increase to 40% in the future.<sup>(21)</sup>

### 6.6.2 Survey Questions

The Commission and KPMG Global Health Centre of Excellence, a professional services group, worked jointly to identify the four most important areas that the national inpatient survey needed to address. KPMG produced a report that was then reviewed and tested by the Commission with numerous stakeholders and consumers, including the Commission's expert advisory group on quality and safety indicators.

The following 4 domains were selected:

- Communication
- Partnership
- Coordination
- Physical and emotional needs

To develop a question set, the Commission purchased a license to allow access to the Picker Institute's library of 200 survey questions. They chose a final set of 20 questions for the national inpatient survey and slightly altered the language to make it more appropriate for the healthcare consumers of New Zealand.

Questions were selected to focus on each of the four domains. To achieve this focus, patients are asked to rate their overall experience with each domain using a 10 point scale and then answer two to five questions selected from the Picker Institute library to test for specificity. Patients are also given a "free text" box beside each question to provide examples to support their responses.

The last section of the survey includes questions pertaining to opinions on confidence in the staff, demographic information and a final text box for any additional information the participant wishes to disclose.<sup>(21)</sup>

### 6.6.3 Distribution and Collection

New Zealand's national inpatient survey is mostly collected online for both the simplicity and cost effectiveness. The Commission has found that this method provides the highest response rate and allows for real time updates to the District Health Boards online reports. Currently, nearly 80% of New Zealand's population has access to the internet. Patients will be given the option of participating in the survey via post and "in situ" surveying if they do not have internet access to reduce the risk of an unrepresentative sample. "In situ", or 'on site', responses are collected during a patient's hospital stay.

Each District Health Boards is responsible for collecting all patient data during the selected survey sample period in accordance with the data extract and file format rules. The data is uploaded on the same day to a secure portal for the national survey and reporting system provider to conduct a random selection of participants. Those patients with an email on file will be given preference. Participants selected who do not have an email on file will be contacted via SMS (text) or post. Both email and SMS survey invitations are sent out on the day of the patient data upload, nine days after the conclusion of the sample period. District Health Boards are responsible for coding the paper surveys and mailing them to participants, so these invitations will not be mailed out on the same day.

All participants are provided with a unique survey link to either click on or type in to submit their response. The link provided in the email survey expires once the survey is completed to ensure that only one response is submitted per patient. Both the SMS and postal survey invitations contain a unique code for the participant to type in to access their survey. All online links expire 21 days after the initial survey is sent. Patients that want to return their completed survey via post will have the option to mail it back to the District Health Boards. The District Health Boards will then be responsible for entering the responses into the survey system. Only in areas where there is low internet access and no other practical options will "in situ" collection be permitted by the Commission.

To increase the national survey response rates, the Commission distributes reminder letters to those patients selected to participate in the survey. Reminders are sent seven days after the initial contact.<sup>(21)</sup>

#### 6.6.4 Survey Helpline

The National Patient Experience Project Manager provides assistance as required, and when appropriate refers questions to local level.

#### 6.6.5 Communication

Surveys are sent as soon as possible after the patient's discharge from the hospital to reduce the risk of the patient's circumstances having changed. It can take up to three months to update the District Health Boards systems following a patient's death; therefore, to mitigate the risk of sending a survey following a patient's death, the Commission includes a "sensitivity" statement in the correspondence.

In an effort to further open up communication for patient feedback, survey participants are given the option of providing contact information in their survey response if they wish to speak to a District Health Board representative. The District Health Board will receive an email alert if a patient indicates that they would like to be contacted.<sup>(21)</sup>

#### 6.6.6 Analytical Methodologies and Tools

Following collection of the national survey responses, the national survey and reporting system provider sends the data to the District Health Boards and the Commission for analysis to be conducted. The data analysis is automated and populates the national report. It can be broken into more detail by individual District Health Boards. The free text boxes contain an exceptionally rich source of information. District Health Boards will have the ability to filter comments, view word clouds, and search for specific terms. If any additional analysis is required by the District Health Boards it can be undertaken using the data extract provided by the initial report.<sup>(21)</sup>

#### 6.6.7 Outputs

The Commission is responsible for preparing and publishing the quarterly patient experience reports that present the national results. District Health Boards can review results by logging in to the national survey and reporting system. Both overall scores for each domain and the scores for individual questions within each domain will be available for viewing. The reports can be filtered at a range of levels to allow the results to be viewed in detail.

The survey and report system dashboard will allow District Health Boards to filter results by:

- District Health Board
- Discharge data ranges
- Age
- Gender
- Ethnicity
- Health speciality code
- Facility code
- Admission type
- Optional fields provided in the background extract.

Reports can be downloaded from the dashboard as PDFs, image, and CSV/Excel formatting for easy internal reporting. A survey tracking report will be included to allow District Health Boards to analyse the overall survey response rate and the response rates among the different data collection methods. Additionally, the national patient experience indicators are included in Quality and Safety Indicator reporting.<sup>(21)</sup>

## **6.7 Key Recommendations and Lessons Learned from New Zealand**

The following are key recommendations and lessons learned:

- Ensure that there is a robust communication plan in place with the sector
- View the survey as having a clear quality improvement focus
- Allow for an online approach to future proof the process
- Get your questions and tools right from the outset
- Allow for cognitive testing; slight changes to some questions were necessary due to cultural differences
- There is need for an excellent project manager.

## **7. Conclusion**

The evidence from this International Review clearly identifies that the patient, service provider, regulator and policy developer benefit from a partnership model.

The results from the patient experience surveys provide the single largest reliable source of evidence on patient's experience of care in the acute care sector. Based on the findings in this review, in order to attain the greatest value from the patient experience survey the most advisable course of action is to develop a partnership model to leverage the findings to provide the greatest value across the healthcare sector. The findings inform patients about the quality of care available, provide service providers with comparable intelligence about the quality of experience that patients have while in their care, identify potential risks and challenges in care provided to the regulator, inform and improve quality of care, and inform national health and social care planning.

This international review has demonstrated the benefits of a partnership approach, a number of the benefits are outlined below. It has equally highlighted the restrictions that result from an independent approach, limiting the timeliness and cohesiveness of the response, and reducing the potential for subsequent improvements.

The benefits of the partnership approach include:

- Ensuring the patient comes first across the whole health system. The wealth of data from the patient about their experience, allows each organisation within the partnership the opportunity to improve the patients experience and quality of care.
- In terms of investment, a partnership approach can facilitate shared funding, providing significantly better value for money for the patient.
- The combined skill-sets of all three partners will ensure that the data is leveraged to improve all facets of healthcare.

## **7.1 Findings**

### **7.1.1 Objective**

The overall objective of conducting a national patient experience survey within each of the jurisdictions examined was to hear the patient's voice as it is recognised as an essential tool to inform and improve quality of care provided.

### **7.1.2 Commitment**

The budget commitment varied depending on the model and methodology adopted. Every jurisdiction reviewed subcontracted a portion of the programme to an approved survey contractor to administer the survey. A team of four to six members from government and regulatory authorities was typically required year round to manage the survey programme.

### **7.1.3 Legislative Requirements for Data Protection**

Each jurisdiction's legislative requirement around data protection is a significant consideration for patient experience surveys, considering the large amount of personal data required to conduct this process. All of the jurisdictions examined have a legal remit to collect personal data and share the personal data with a third party if the purpose is to improve the quality and safety of care for the patient. To maintain anonymity, survey participants are assigned a unique identification number.

### **7.1.4 Governance Arrangements**

Each jurisdiction reviewed has a team in place with representatives of each partner to agree on the development and delivery of the national patient experience survey.

### **7.1.5 Survey**

A significant number of jurisdictions reviewed distribute the national patient experience surveys via post. There are benefits to distributing the surveys electronically, but in most of the jurisdictions reviewed the response rate is low. The online version has the added advantage of being the most cost and time efficient method allowing real time updates to be available to service providers. This solution also future proofs this programme of work.

In relation to the postal process; reminder letters and packs sent out to the non-responders were found to significantly increase the response rate.

The survey sample is selected from each hospital during a set sample period. All jurisdictions use approved survey contractors to distribute the survey packs to the participants. The majority of the jurisdictions reviewed used questions from the Picker Institute Europe's library to allow for international comparisons.

#### **7.1.6 Outputs**

The survey results are analysed and reported in each of the jurisdictions examined. The results are published in a national report and can be distilled into more detail at a local level. Free text comments from patients were found to be a rich source of information at hospital and departmental level.

## **7.2 Next Steps**

The Department of Health, Health Service Executive and HIQA have developed a partnership that are working together alongside patient representatives to develop a model and methodology for a National Patient Experience Survey.

The National Patient Experience Survey will be implemented in 2017.

## Appendix 1: Organisations and participants that contributed to review

HIQA would like to thank the below organisations and participants for providing their time and knowledge to inform this International Review.

Table 1: Conference call organisations and participants

| Date of Conference Call | Organisation                              | Type of Organisation  | Title  |
|-------------------------|---|---|--|
| 17/12/14                | Scottish Government                       | Government Body: Responsible for managing the Patient Experience Surveys in Scotland                    | Head of Health Analytical Services<br>Principal Researcher     |
| 23/12/14                | Picker Institute Europe                   | Charity conduct surveys on behalf of the NHS  | CEO<br>Director of Research and Policy                         |
| 07/01/15                | Patient Experience and Evaluation Denmark | Research Centre conducts surveys on behalf of the Danish health system                                  | Director<br>Project Manager, LUP                               |
| 19/01/15                | Care Quality Commission                   | Regulator: Commissions a 3 <sup>rd</sup> Party to conduct surveys on their behalf                       | User Voice Development Manager                                 |
| 21/01/15                | Healthcare Improvement Scotland           | Regulator – user patient experience survey data from the Survey commissioned by the Scottish Government | Head of Data<br>Measurement and BI                             |
| 22/07/2015              | Health Quality and Safety Commission      | National Quality Improvement Body   | Director of Health Quality and Evaluation<br>Programme Manager |



## Appendix 2: Surveys conducted by each jurisdiction reviewed

Table 2 below outlines the surveys that are currently conducted by the jurisdictions in this International Review.

*Table 2: Current surveys conducted in each jurisdiction*

| Jurisdiction | Surveys Conducted  |
|--------------|--|
| Scotland     | <ul style="list-style-type: none"> <li>▪ Inpatient Patient Experience Survey</li> <li>▪ Health and Care Experience Survey (General Practitioners (GP) Services)</li> <li>▪ Maternity Care Experience Survey</li> </ul> |
| Denmark      | <ul style="list-style-type: none"> <li>▪ Inpatient Patient Experience Survey</li> <li>▪ Outpatient Patient Experience Survey</li> </ul>  |
| England      | <ul style="list-style-type: none"> <li>▪ National Children's Inpatient and Day Case Survey</li> <li>▪ Inpatient Survey (Annually)</li> <li>▪ Community Mental Health Survey</li> <li>▪ Maternity Survey</li> </ul>     |
| New Zealand  | <ul style="list-style-type: none"> <li>▪ Inpatient Patient Experience Survey</li> <li>▪ Primary Care Patient Experience Survey</li> </ul>  |

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