



**National Care  
Experience  
Programme**

A large, dark blue circular graphic occupies the lower two-thirds of the page. It features several thick, white, curved lines that sweep across the circle, creating a sense of movement and depth. There are also three small, white, tilted squares scattered within the blue area, one near the top left and two near the center.

**International Review of  
Nursing Home  
Experience Surveys**

## About the National Care Experience Programme

The National Care Experience Programme (NCEP) seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The NCEP has successfully implemented the National Inpatient Experience Survey for three years, the National Maternity Experience Survey in 2020, and is currently developing three further surveys covering end-of-life care, older persons' care and maternity bereavement. These surveys will be ready for implementation by the end of 2021.

The National Inpatient Experience Survey is an annual survey providing patients with the opportunity to describe their experiences of public acute hospital care in Ireland. The purpose of this survey is to learn from patients' feedback to find out what is working well in our hospitals, and what needs improvement. The HSE responds to the results of the National Inpatient Experience Programme by developing quality improvement plans at the national, hospital and hospital group levels. In addition, the results of the inpatient survey inform national policy and HIQA's healthcare monitoring programme.

The National Maternity Experience Survey offers women the opportunity to share their experiences of Ireland's maternity services. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their baby receive. The first National Maternity Experience Survey was completed in 2020, with over 3,200 women who gave birth on October and November 2019 sharing their maternity care experiences.

A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

# Contents

<b>1. Introduction .....</b>	<b>5</b>
1.1 Aims and objectives.....	7
1.2 Methodology .....	7
1.3 Structure .....	7
<b>2. Summary of findings.....</b>	<b>9</b>
2.1 Objectives .....	9
2.2 Governance arrangements .....	9
2.3 Legislative requirements for data protection .....	10
2.4 Ethical approval.....	10
2.5 Communication .....	10
2.6 The Survey .....	11
2.7 Survey methodology.....	12
2.8 Outputs.....	14
2.9 Impact.....	14
Methodologies for international nursing home experience surveys.....	16
<b>3. Australia .....</b>	<b>17</b>
3.1 Background .....	17
3.2 Objectives .....	17
3.3 Governance arrangements .....	18
3.4 Data protection and consent.....	18
3.5 The Survey .....	19
3.6 Outputs and impact of the survey.....	21
3.7 Recommendations and key lessons learned from Australia .....	22
<b>4. The Netherlands .....</b>	<b>23</b>
4.1 Background .....	23
4.2 Objectives .....	23
4.3 Governance arrangements .....	24
4.4 Data protection and consent.....	24
4.5 The Survey .....	24
4.6 Outputs and impact of the survey.....	27
4.7 Recommendations and lessons learned from the Netherlands .....	28
<b>5. United States.....</b>	<b>29</b>

5.1 Background .....	29
5.2 Objectives .....	29
5.3 Governance arrangements .....	30
5.4 Data protection and consent.....	30
5.5 The Survey .....	31
5.6 Outputs and impact of the survey.....	34
5.7 Recommendations and lessons learned from the United States.....	34
<b>6. Canada .....</b>	<b>36</b>
6.1 Background .....	36
6.2 Objectives .....	37
6.3 Governance arrangements .....	37
6.4 Data protection and consent.....	37
6.5 The Survey .....	38
6.6 Outputs and impact of the survey.....	42
6.7 Recommendations and lessons learned from Canada.....	43
<b>7. Conclusion .....</b>	<b>44</b>
7.1 Findings.....	44
7.2 Next steps.....	44

## 1. Introduction

Person-centred care has been a key domain of quality in healthcare for well over a decade.<sup>1</sup> The basic premise of focusing care around the person using a health and social care service and responding to their needs and preferences is well established as a component of high-quality healthcare.<sup>2</sup>

Measuring person-centred care involves collecting feedback on the experiences of people who use health and social care services. This feedback is a key indicator in identifying where expectations in health and social care are being met and where they are falling short. Patient experience, or the experience of those who use health and social care services, is now recognised as one of the three pillars of quality in healthcare, alongside clinical effectiveness and patient safety.<sup>3</sup> Evidence has shown that the three pillars of quality should be looked at as a group and not in isolation.<sup>4</sup>

In recent years, health and social care experience surveys, which capture the experiences of those who use these services, have been implemented at a national level in many countries. Significant benefits have been gained for all stakeholders from capturing this experience, including service providers, people who use the services, the public and national policy developers and regulators. For example, care experience surveys or other methodologies can lead to informed choice for people who use services, enhanced recovery for patients, improved productivity and efficiency for healthcare providers, and lower staff turnover and absenteeism.<sup>5,6</sup> They provide a means by which patients and people who use services can be engaged, active and informed in their own care.

For healthcare providers, the data collected by care experience surveys helps to identify areas for improvement, provide assurance in the care being provided, and benchmark care experience both nationally and internationally. As care experience surveys are tools which inform healthcare management of the quality and safety of care provided, they drive accountability across the healthcare system.

Furthermore, they provide legislators with definitive data to inform policy development and implementation. They also inform the development of national care standards, in addition to monitoring and regulation programmes for services.

In Ireland, national health policy highlights the importance of engaging with people who use health and social care services and capturing their care experiences to inform quality improvements in healthcare.

The Department of Health's Statement of Strategy 2016-2019 commits to the creation of a more responsive, integrated and person-centred health and social care service.<sup>7</sup>

It plans for the implementation of national strategies, which are underpinned by the engagement of people that use health and social care services, for example the National Maternity Strategy 2016-2026<sup>8</sup> and the National Cancer Strategy 2016-2026.<sup>9</sup> Similarly, Sláintecare, the 10-year, cross-political party strategy for healthcare and health policy in Ireland, advocates that “the voices of current service users and citizens must therefore be at the heart of healthcare reform, and success will be judged in terms of patient experience and outcomes and the overall health of our population”.<sup>10</sup> Sláintecare explicitly sets out the development and expansion of systems to capture patient experience.<sup>10</sup>

In Ireland, the inaugural National Inpatient Experience Survey was successfully conducted in May 2017, when over 13,000 patients, representing a 51% response rate, chose to share their experiences of care in Ireland’s public acute hospitals.<sup>11</sup> The findings helped to inform national and hospital-level quality improvements across the acute inpatient hospital sector.

At the national level, the Health Service Executive (HSE) established an Oversight Group to review the findings of the National Inpatient Experience Survey and to develop a systematic plan for improving patient experience across acute hospitals. This led to the establishment of the National Healthcare Communication Programme and the launch of the National Food, Nutrition and Hydration Policy for Adult Patients in Acute Hospitals. At local level, every hospital designed a quality improvement plan to address the findings.<sup>12</sup>

The Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health established the National Care Experience Programme (NCEP) to run the National Inpatient Experience Survey and expand the programme to cover other areas of health and social care. This expansion led to requests for care experience surveys across a range of other areas, including the experiences of older people in Ireland.

In addition to the prioritisation set out in the NCEP Strategy 2019-2021,<sup>13</sup> a recommendation was made in the COVID-19 Nursing Homes Expert Panel Review report (published in July 2020) which stipulated that expansion of the programme to nursing home residents be progressed at pace.<sup>14</sup> There is currently no systematic approach used to capture the care experiences of nursing home residents in Ireland.

## **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 survey of the experiences of nursing home residents.

There is no national standardised model in place to collect data on the care experiences of nursing home residents in Ireland. This report aims to identify how international organisations and agencies collect and use nursing home residents' care experience data. Through identifying international best practice, this review will help inform the National Care Experience Programme on the most appropriate and effective approach to implement a national nursing home experience survey in Ireland.

## **1.2 Methodology**

A scoping review of international literature on the development and implementation of a national nursing home experience survey was conducted in the first instance. In defining the inclusion criteria for selecting countries and surveys, it was decided that access to technical and methodological documentation, key personnel and affiliation with reputable organisations and agencies would inform the review process.

Based on these criteria, four countries were selected from the review for inclusion in this document. It will outline the operational, governance and reporting processes employed in each survey.

## **1.3 Structure**

This document presents a summary of the findings from the international review which was undertaken to inform the development of an appropriate model and methodology for a survey of nursing home residents in Ireland.

The four international jurisdictions reviewed in detail in this report are:

- Australia
- The Netherlands
- United States of America
- Canada (British Columbia).

Findings for this review were compiled from national documentation from each country and detailed discussions with key relevant personnel who were involved in the development and or management of nursing home care experience surveys within each country. Appendix A lists the personnel who were consulted within each organisation.

Findings in relation to each of the four selected countries are presented in this report under the following headings:

- objectives
- governance arrangements
- legislative requirements for data protection
- ethical approval
- communication
- the survey
- survey methodology
- outputs
- impact.

This review focuses on the model and methodology used in each jurisdiction, in particular:

- operational perspectives and associated requirements, survey model and methodology, resources, governance structures, information governance, administration and implementation of the survey model.
- administrative requirements, including communications and distribution of survey material and resources.
- outputs and reporting structures, that is, what is reported and in what format and how survey findings are used to improve care.

The specific survey question libraries are not reviewed in this document as they are evaluated as part of a separate process.

A summary table of the models and methodologies outlined in this report can be found in Appendix B.



## 2. Summary of findings

A summary of findings for care experience surveys of nursing home residents is set out below.

### 2.1 Objectives

The overall objective of conducting a survey of residents in nursing homes in each of the countries reviewed was to listen to the collective voice of residents in order to evaluate the quality and standard of care provided in these settings. The survey findings are used to enhance accountability, inform policy and ultimately to improve the quality of care provided to residents.

### 2.2 Governance arrangements

Governance arrangements for the surveys varied between countries. In some instances, the regulation and formal accreditation requirements for long-term care residential facilities plays a key role, particularly in Australia and the Netherlands. Work is underway in Canada to identify a suitable survey tool which will be incorporated into accreditation programmes. On the other hand, the survey utilised in the United States of America was introduced as part of a federal initiative within a broader suite of health and social care survey programmes.

All surveys reviewed had a dedicated team in place to agree on the development and delivery of the survey and most of the surveys reviewed were underpinned by a partnership approach to governance which included:

- core survey team or organisation
- research agencies and academic professionals and experts from universities
- health and social care regulators
- care provider organisations from the public and private sectors
- policy-makers
- representatives of nursing homes residents and their family members
- advocacy groups.

In terms of operational governance arrangements, national accreditation bodies were tasked in undertaking the role of an independent survey coordinator, while in other countries certified or authorised survey vendor organisations were used to coordinate the survey administration and data collection process. Both approaches helped to reduce the administrative burden that would otherwise be placed on the care provider organisation, while also helping to promote the integrity of the survey by working to reduce any potential bias which may arise as a result of more direct care provider involvement.

## 2.3 Legislative requirements for data protection

Legislation around data protection is a significant consideration for care experience surveys in light of the large amount of personal information required to conduct these surveys. All countries included in this review collected, managed and processed the survey data in line with data protection obligations within their jurisdiction and used the information to evaluate and improve service provision.

To preserve data protection and to ensure respondent confidentiality is upheld, most countries employed the use of a unique identification number for each respondent in order to maintain the anonymity of the respondent.

## 2.4 Ethical approval

In some instances, ethical approval was not required as the surveys were underpinned by the processes supporting the regulation and accreditation of a long-term residential facility; these resident surveys were developed in a way which built on existing processes and were conducted inform the overall audit process. In other cases, ethical approval was sought by academic partners in order to test or pilot survey tools within a sample of representative centres. Consent in each of the surveys was informed and obtained from participants in advance of the survey, in line with obligations.

Surveys of residents and or their representatives\* were identified as a tool used in regulation of services, consumer choice and quality improvement. As such, they were regarded as a key resource in the delivery of long-term residential care and service evaluation and improvement.

## 2.5 Communication

The significance of promoting the survey to the target population, in order to increase response rates, was highlighted as key to success and there were various methods used to promote the survey and to inform residents and their representatives of the surveys. Most countries used resources such as posters, leaflets and information letters to inform prospective respondents about the upcoming survey and to also provide information on opt-out procedures and key data protection elements.

In the surveys reviewed, communication was primarily issued from independent survey organisations rather than the individual care providers.

---

\* Representatives is the term commonly used across reviewed surveys to refer to a resident's family member or friend who may act on their behalf.

Care providers were normally asked to coordinate the display of posters in their respective centres but direct communication with residents in the form of information packs, including letters, tended to come from external survey organisations.

This helped to preserve the principles of credibility, integrity and independence of the survey, reducing potential sources of bias which may impact on the final survey results.

## 2.6 The survey

### Eligibility criteria

There was a degree of variation in the application of eligibility criteria within each of the surveys in this review. Some surveys used less than two eligibility criteria while others involved a more extensive and detailed list.

There were a number of inclusion criteria applied across the reviewed surveys, with residents in long-term care homes featuring as the typical sample population. Some countries applied a minimum time frame within which eligible residents had lived in a centre, while others did not stipulate such a criterion. Of note, one country devised separate survey tools and modes of administration for long-term and short-term residents. In general, family members or friends tend to be invited to participate on behalf of residents who were unable to participate directly themselves.

There were a number of exclusion criteria applied across the surveys reviewed, including:

- residents who did not meet the minimum period of residency in the centre, for example, those admitted to a centre less than a month prior to the survey
- residents with severe cognitive or psychiatric problems or who were deemed very ill, of poor health status or in a terminal phase of illness
- residents who passed away prior to the interview period
- residents who had been discharged prior to the commencement of the survey
- residents who were not present in the care home during interview times.

### Survey respondent selection

Selection of survey respondents was similar across the majority of surveys, with some nuances observed throughout the review.

The most common method of accessing information on residents in order to administer the survey was by utilising the person's record on file in their respective nursing home. This was commonly obtained through a formal data request which was issued to the participating nursing homes and a dedicated process was set up in the form of resident census templates to fulfil such requests.

Due to the prevalence of cognitive impairment in this population, care providers were normally asked to provide a list of eligible residents who were deemed to have sufficient cognitive ability to participate in a structured interview. This census list of eligible residents was then provided to the interview team and a random or systematic sampling technique was normally used to select residents for interview.

In the event of a resident being unable to participate in an interview due to cognitive impairment, a representative was invited to respond on their behalf. The terminology used to define representatives varied across surveys, including: 'family member or friend', 'care representative', 'most frequent visitor', 'spouse or other' and 'caregiver'. In some cases, representatives were asked to complete the standard resident survey tool, while in other instances, the standard resident questionnaire was adapted slightly for administration to representatives. In one country, all representatives were invited to participate (rather than simply those who were asked to respond on behalf of a resident) and a dedicated survey instrument was developed in order to evaluate their experience as a visitor to the centre.

### Question pool

Unlike surveys of acute inpatient care, an international library of validated questions is not available for nursing home surveys. Countries or regions which undertake surveys of this kind developed, tested and piloted their own questions. In some cases, specific questions were adopted from existing surveys and merged to form a survey instrument relevant to the context of the country or region.

The inclusion of free-text questions at the end of each survey was a prominent feature of the surveys reviewed. This type of qualitative data provides a rich source of information, providing detailed insights and informative data which can be used to demonstrate areas of good experience and also to inform quality improvement initiatives. In some cases, respondents were also asked to rate their overall experience of care, normally on a scale of 0-10.

In addition to the use of quantitative and qualitative questions, the surveys reviewed also included a number of demographic information questions relating to the resident and or their representative.

## 2.7 Survey methodology

### Mode of contact

A combination of in-person structured interviews and postal surveys was commonly used across the four jurisdictions. All countries reviewed used in-person structured interviews to administer the survey to long-term nursing home residents. While postal surveys were normally administered to appointed representatives of residents,

the postal survey option was not used as a primary mode of survey administration to nursing home residents in any of the countries reviewed.

While structured interviews were more cost and resource-intensive, this approach was deemed to be the most appropriate mode of administration for nursing home residents in all cases as it ensures that the direct resident voice is captured effectively.

Certified or authorised survey vendors were commonly used to either administer surveys via interview with residents or to issue postal survey packs to representatives. In one country, the survey vendor sent postal packs directly to the care providers and requested distribution of the packs to the representatives of residents. In the case of the surveys which are aligned with regulatory or accreditation cycles, the regulatory body and accreditation auditors were responsible for coordinating the survey.

### Mode of response

A dual approach to the mode of response was common across the countries reviewed, with a combination of in-person structured interviews and postal surveys used. All countries reviewed utilised face-to-face structured interviews with residents of nursing homes. If a resident was unable to participate in the interview, an appointed representative of the resident was normally invited to respond on their behalf, or from their own perspective as a visitor to the centre, using a postal survey. One country relied solely on the use of interviews with residents or their representative, while another country offered two response options for representatives to choose from, either postal or online returns. Postal reminder letters and packs were normally sent out to non-responders in order to increase the response rate, while participants involved in structured interviews were approached up to three times in some jurisdictions in order to increase participation rates.

The use of telephone surveys was not typically offered as a mode of response in the four countries reviewed.

### Frequency

There are different approaches used in the frequency of undertaking surveys of nursing home residents. In some cases, the surveys were conducted as part of routine accreditation cycles and data is gathered over a longer period of time, aligned with the scheduling of accreditation audits. In other jurisdictions, surveys are not conducted on a routine basis beyond the initial survey cycle, but plans were set out to repeat the survey after a number of years to analyse trends over time.

## 2.8 Outputs

Survey responses are analysed and reported in each of the countries examined, with the publication of survey results deemed to be of great importance in order to inform public reporting, enhance accountability and drive quality improvement initiatives. The results of surveys tend to be published at national (or provincial level, where relevant) and in some cases are disseminated in a tabular or summary format at a local level. Each organisation noted the challenges of publishing detailed centre-level data primarily due to concerns over preserving the anonymity of respondents in smaller-scale facilities.

Where surveys are conducted on an ongoing basis, for example, as part of regulatory or accreditation audits, the data is collated periodically to inform an overview report to show findings gathered over a two year period, for example. In the case of surveys linked with accreditation audits, resident surveys and corresponding audit reports for each centre are published online side-by-side.

In contrast, the CAHPS Nursing Home Survey provides two distinct types of report: public reports which can be accessed online by members of the public, and also private reports which can only be accessed by the individual care providers. Private reports provide summary data on trend analyses and sets of comparator data, such as local or state averages or percentiles, which can help to inform and drive quality improvement within each centre.

Nursing home experience survey reports are published for members of the public to assess the suitability and performance of individual long-term care facilities and identify the most appropriate centre for themselves or their loved ones. As such, alongside the use of survey findings to inform quality improvements, the outputs of some surveys also serve as accessible consumer information reports.

Research bodies often express interest in these survey outputs, in particular the publication of results from the development of surveys and the subsequent piloting of tools within this target population of older cohorts in society and other nursing home residents. There are a number of academic publications available online which disseminate this type of information. This is driven partly due to the involvement of research agencies and university-based teams during the development of survey tools.

## 2.9 Impact

The requirement to act on findings of nursing home surveys varies considerably among the countries reviewed. Certain jurisdictions are required to use survey findings to increase quality and performance to ultimately improve compliance with national standards and mandatory accreditation guidelines, while others are not.

Generally, the direct impact of nursing home experience surveys is not readily reported however.

Nevertheless, the clear benefits of conducting such surveys are acknowledged and they are regarded as highly significant for all stakeholders, including residents, their representatives, care provider organisations, regulators and policy-makers. This review indicates that there is a clear understanding around the importance of conducting this type of survey in order to obtain invaluable insights from the collective voice of residents in long-term care to understand their lived experiences and to improve the care provided.

## **Methodologies for international nursing home experience surveys**



## 3. Australia

The following is a review of the Consumer Experience Survey of Residents in Residential Aged Care Services; a survey specifically designed to accompany and inform the accreditation process of residential aged care services in Australia.

### 3.1 Background

The Aged Care Quality and Safety Commission (the Commission) is responsible for the national regulation of aged care services in Australia and works to protect and enhance the health, safety and wellbeing of people in receipt of aged care services.<sup>15</sup> These government-funded services refer to the supports provided to older people who require help in their own home or who can no longer live at home and instead live in residential care in aged care (nursing) homes and short-term respite care.<sup>16</sup> The Commission also has responsibility for assessing, accrediting and monitoring aged care services to ensure the provision of high-quality care to older persons and compliance with standards.<sup>15</sup>

As part of the accreditation process, which is mapped against the Aged Care Quality Standards, site audits are conducted in residential aged care services.<sup>17</sup> These audits involve the use of observations and a review of key documentation which serve to assess the quality of care and services provided by the service in line with the Standards. The audits also typically include conversations with residents to provide an opportunity for those individuals to share their lived experiences of residing in the centre.<sup>15</sup> All residential aged care services in Australia are obliged to comply with the accreditation process and the Standards in order to receive government funding.<sup>15,17</sup>

In 2017, a decision was made to build on these audit practices and researchers from the Australian Institute for Primary Care and Ageing (AIPCA) in La Trobe University were commissioned to develop and pilot a set of core structured questions to be used as part of more structured and systematic resident experience interviews during audits.<sup>15</sup> The questions were incorporated into the routine regulatory audits which support the accreditation process for aged residential care services. The findings of the survey were then reported in a Consumer Experience Report, along with the completed audit report, for the residential centre.<sup>18</sup>

### 3.2 Objectives

The purpose of the Consumer Experience Survey of Residents in Residential Aged Care Services is to provide information about residents' experiences of the quality of care they received in residential aged care services in Australia.

Furthermore, the Commission stipulated that all survey results be published to firstly inform quality improvement initiatives, and secondly to provide public information about the performance and quality of residential aged care services.<sup>18</sup>

### **3.3 Governance arrangements**

The governance of long-term residential care facilities in Australia is categorised as private, not for profit and government funded. For the purposes of this survey, all government-funded centres were included in the sample as part of the accreditation process for aged care services.

The Aged Care Quality and Safety Commission was responsible for undertaking the consumer experience survey of residential aged care services and worked with a number of agencies to develop an appropriate survey tool.

A working group was convened which comprised of stakeholders and industry representatives to inform the development of an appropriate model and methodology.

To ensure the development process was rigorous and underpinned by research, the Commission engaged with the Australian Institute for Primary Care & Ageing which is based in La Trobe University to conduct research, develop, pilot and statistically test the survey questions.<sup>19</sup> A team of researchers from Sydney University was responsible for leading the literature review to identify the quality domains of interests to individuals living in residential aged care.<sup>20</sup>

### **3.4 Data protection and consent**

Personal information pertaining to residents was obtained from the long-term care facilities in advance of the scheduled audit. Specifically, a named list of residents was provided to the team of assessors who were responsible for auditing residential aged care services on behalf of the Commission and a sample of residents was selected from the list. This information was used to administer the survey to residents and was managed in line with data protection obligations and legislation.

Survey participation was entirely voluntary and residents who initially chose to participate were also informed that they could decline to participate in the interview at any point. Auditors informed participants that their future care would not be affected in any way, regardless of their participation status.

As regards the publication of reports, the resident experience reports do not identify individual residents and they are published as part of the broader accreditation process whereby minimum sample requirements for interviews can be met in order to protect respondent anonymity.<sup>21</sup>

### 3.5 The survey

The Commission's predecessor, the Australian Aged Care Quality Agency, commissioned the University of Sydney to undertake a literature review to identify the drivers of choice and domains of interest to individuals who use residential aged care in Australia.<sup>20</sup> The need for a standard report on resident experiences in these settings prompted the Agency to commission this piece of research into the quality of services in 2016.<sup>22</sup>

La Trobe University was commissioned to build on existing audit processes and was tasked with developing a core set of interview questions for use during accreditation site audits of residential aged care services.<sup>19</sup> The core interview questions were intended to support the development of a standard routine report on the quality and standard of care experienced by residents in residential aged care facilities. The team from La Trobe University was responsible for conducting research, along with the development and statistical testing of the interview questions. Initially, a set of 24 questions were piloted across a number of residential aged care facilities in Melbourne, involving a representative group of 140 residents and 48 representatives. Almost half of the representatives were an adult child or a daughter or son-in-law of a resident.<sup>19</sup>

The pilot resulted in the identification of a set of 10 core questions which best described the experiences of residents in a centre, informed by stakeholder engagement and the research undertaken by Sydney University.<sup>20</sup> In general, the specific centre that the respondent lived in was the most significant variable in differentiating between responses; this indicated that the interview questions illustrated the ability to differentiate the experience of residents living in different centres. Efforts were made to ensure that the predictors were based on service provision and not potentially confounding variables such as gender.<sup>19</sup>

The most useful questions were found to be short and clear, with a *Never – Always* set of response options noted to be the most preferred format. The inclusion of a middle response option was reportedly useful for respondents who were unsure as to how to answer a question. These response options were also accompanied by a visual analogue scale which was found to be very helpful. Survey respondents were asked to select answers offered both in words and in illustrations depicting 'grumpy' through to 'smiley' faces.<sup>15,19</sup>

Some of the topics addressed in the core questionnaire included, the care provided by staff, respect from staff, food and mealtimes, daily activities and residents' perception of safety in the centre. The question set was linked with some of the themes and domains within the Aged Care Quality Standards.<sup>17</sup>

The final question set comprised of 10 quantitative questions which were deemed to have appropriate characteristics as both individual items and as a scale. The questionnaire also contained two qualitative questions which served to provide rich insights into the lived experiences of residents.

### The sample

The sample comprised of eligible residents in residential aged care services in Australia, or their care representative if the resident was unable to participate in the interview.

The sampling technique required that a list of named residents from each aged care residential service be provided to the audit team in advance of the audit. From this list, a sample of eligible residents was chosen using systematic random sampling technique, to reduce the risk of selection bias; a minimum sample of 10-12% of residents from each centre to ensure consistency throughout the process. If a resident did not wish to participate, a replacement procedure was used, whereby the next resident on the list was invited to participate instead.

Where necessary, care representatives (normally a family member or friend of the resident) were invited to contribute to the sample on behalf of a resident by acting as a proxy respondent.

As part of the pilot process, the team undertook research on the sampling process. While feedback on the sampling was generally positive, the assessors recognised the time involved in locating residents and finding a suitable location to conduct the interview. Similarly, feedback from representatives suggested that they welcomed the opportunity to be involved in interviews, but assessors acknowledged the time element involved in this element of recruitment.<sup>19</sup>

### Distribution and data collection

The survey was administered by a team of auditors, as part of accreditation audits, on behalf of the Aged Care Quality and Safety Commission. Data collection for this survey is collected in line with scheduled accreditation audits, rather than during a defined survey period. To promote the survey, providers of aged care services were asked by the Commission to inform their residents and representatives about the upcoming audit and the potential opportunity to provide feedback on their experiences of care to the audit team on the day of inspection.

In order to build on existing processes and structures, face-to-face structured interviews were conducted by the audit team with the selected residents.

The use of proxy respondents was also permitted as part of data collection for this initiative if a resident was unable to take part in the structured interview.

As part of a pilot study, a review of systematic differences between the responses provided directly by residents and those by family members revealed some differences in item-level data, for example food, but no difference in total scores.<sup>19</sup>

Regardless of whether a resident or their representative takes part in the survey, a face-to-face interview was the default mode of survey administration and no other mode was used. However, if a person wishes to provide feedback on their experience outside of this formal process, there is a forum for them to do so via telephone but their experience would not be included in the reporting structures.<sup>21</sup>

### Communication and publicity

To promote the survey, providers of aged care services were asked by the Commission to inform their residents and representatives about the upcoming audit and the potential opportunity to provide feedback on their experiences of care to the audit team on the day of inspection. This involved the use of posters and verbal communication in order to promote participation rates within each centre.

### Response rate

Data was gathered over a period of time as part of scheduled routine accreditation audits rather than during a defined survey period. Between 1 July 2017 and 30 June 2018, over 15,000 interviews were conducted in over 1,100 residential aged care services.

Overall, between 2017 and 2019, over 31,000 individuals from across 2,070 aged care residential services in Australia took part in resident experience surveys.<sup>15, 22</sup>

## 3.6 Outputs and impact of the survey

As part of the formal accreditation process, the Commission publishes Accreditation Audit Reports for each residential aged care centre. These reports display the findings from accreditation audits and demonstrate the compliance of the centre against the standards. The reports are designed to be accessible to a wide range of stakeholders and written in a manner which is easily understood by the public.

As part of these audit-based reporting structures, the corresponding resident experience report was published alongside the audit reports to provide additional information on the lived experiences of residents until December 2019.

The reports for each service displays the responses of participating residents to 10 key questions which covered various aspects of the standards. The qualitative responses were not reported on as part of these publications.

These resident experience reports continued to be published on a routine basis until structured resident interviews of this type were withdrawn from the process and were no longer undertaken as part of site audits from December 2019.

Separately, after one year's data collection in 2017, it was agreed that a sufficient volume of data had been gathered to allow for analysis of the aged care sector's experience. The resident experience data was analysed in order to obtain a sense of the variance within and between services and the overall variance of the aged care residential sector results. SPSS and MPlus8 were used to conduct analyses.

A report was compiled which provides a rich overview of the areas where services were doing well and areas where improvement were required.<sup>22</sup> The data involved accounts from 17,195 residents living in 1,159 residential aged care services. The analysis set out to examine differences in responses between groups, including differences in means and spread, in addition to examining the strongest predictors of responses.<sup>22</sup> The report showed how certain individual characteristics of residents had an impact on results, along with aspects of the service itself and how these factors influence the responses.<sup>23</sup> A subsequent report was published in 2019 which contained data from over 31,000 residents from across 2,070 residential centres.<sup>24</sup> The aim of this report was to summarise the combined data and survey results from 2017-2018 and 2018-2019 and perform analyses to identify factors and variables associated with positive responses.

### **3.7 Recommendations and key lessons learned from Australia**

The benefits of using a systematic and structured forum through which to capture residents' experiences was clearly noted in documentation and also from the perspective of key personnel who contributed to the review.

There was acknowledgement around the work and time involved in conducting structured interviews in accreditation audits. Nevertheless, while the process is slightly more time-consuming for the broader accreditation site audit, the interviews with residents are extremely valuable in informing the overall process of accreditation and ultimately, drive quality improvement across aged care services.

When engaging with nursing home residents, it is important to be cognisant of the prevalence of cognitive impairment and some of the associated challenges.

Short, face-to-face structured interviews were deemed to be the most appropriate mode of administration in this instance, with the use of visual analogue scales available in order to support the resident in their response to the questions. It was strongly recommended to carefully pilot survey administration with a small sample of service users in advance to ensure the tool is fit for purpose.

## 4. The Netherlands

The following is a review of the Consumer Quality Index Nursing Home Care Survey; an instrument designed as part of the Consumer Quality-Index national standard in the Netherlands to support the measurement and comparison of individuals' experiences in healthcare.<sup>25</sup>

### 4.1 Background

As the demand grows for transparency and accountability around patient-centred care and the management of performance and quality improvement across health and social care services, the implementation of user experience surveys is growing. However the scope, aims and tools used to undertake surveys varied widely across services in the Netherlands which reduced the opportunity for systematic comparisons between care providers and effective monitoring of quality trends over time.<sup>25</sup>

Therefore, in 2006 the Dutch Ministry of Health mandated the development of a national standard for the measurement and comparison of individuals' experiences in healthcare, called the Consumer Quality-Index (CQ-Index).

In the Netherlands, long-term care is typically provided in nursing homes or residential homes (this can be in somatic or psychogeriatric wards or in care units) and in homecare settings. Specifically, the CQ-Index Long-term Care instrument was developed to capture the experiences of people in nursing homes and residential homes as well as in homecare settings.<sup>26</sup> Following the development of this instrument, nursing homes and long-term care facilities were obliged to conduct surveys every two years as part of their accreditation status; certified research organisations were commissioned to collect the data from residents and submit it to a central database.<sup>27</sup> The process focused on capturing the resident experiences of care in the nursing or care home in the past 12 months. The findings were then used to inform public reporting of service provision, benchmarking and nationwide comparisons between nursing homes.<sup>26</sup>

### 4.2 Objectives

The purpose of the CQ-Index Long-term Care Survey is to provide valid, reliable and comparable information about individuals' experiences and their preferences to evaluate the quality of care from the user's perspective which, in turn, can be used by the provider to inform quality improvement, public reporting and accountability. Furthermore, the survey was developed to inform inspection and regulation by the Inspectorate for Healthcare in the Netherlands and also to direct policy monitoring.

### **4.3 Governance arrangements**

The Dutch Ministry of Health mandated the development of a national standard for the measurement and comparison of experiences in healthcare, including the Consumer Quality-Index (CQ-Index) for Long-term Care.<sup>26</sup>

The CQ-Index survey tool used to measure individuals' experiences of long-term care in the Netherlands is owned by the Dutch Centre for Consumer Experience in Health Care.<sup>28</sup> This organisation was responsible for coordinating the development of the CQ-Index Long-term Care questionnaire and the conduct of the survey by certified organisations on behalf of long-term residential care providers in the Netherlands. The Centre is a private foundation which is funded by the Ministry of Health, Welfare and Sports. The CQ-Index trademark is applied to certify that the information compiled about care providers is valid, comparable and reliable.<sup>29</sup>

Certified survey vendors, who are authorised to conduct CQ-Index research were employed to conduct the surveys on behalf of care provider organisations.

### **4.4 Data protection and consent**

A named list of residents was provided to the team of certified survey vendors prior to the interview.<sup>30</sup> This information was used to administer the survey and was managed in line with relevant data protection laws and obligations.

Information disclosed by the residents during interviews was managed carefully in line with legislation governing the processing of data, and published reports did not enable linkage of any individual respondents to any centre in order to preserve anonymity and confidentiality.

Ethical approval was not necessary as research supported by interviews or surveys that are not overly taxing for participants are not subject to the Dutch Medical Research involving Human Subjects Act (WMO). Participation in the survey was entirely voluntary and consent was implied by taking part in the interview. Residents were informed about the aim of the survey and that they were entitled to withdraw at any point and that their care would not be affected in any way.

### **4.5 The survey**

The approach which underpins the CQ-Index Long Term Care Survey is based on two key principles: the CAHPS method<sup>31,32</sup> and the QUOTE method,<sup>33</sup> with the main focus on resident experience rather than resident satisfaction. The model is therefore based on whether certain processes or events occurred from the perspective of the resident. As part of this survey, the inventory of experiences is combined closely with values and certain expectations in relation to the care received.



As such, residents are asked about their lived experiences and also about how important particular experiences are to them; combining experiences as well as their relative importance helps to inform the determination of priorities for quality improvement initiatives to be undertaken by providers in response to survey findings.<sup>34</sup>

At the time of survey development, there were a number of key resident experience survey instruments in use across long-term care facilities in the Netherlands and the researchers worked to integrate these instruments using similar constructs across the survey groups (residents and representatives). Similar to other instruments in the wider CQ-Index Programme, the long-term care survey was informed by the existing questionnaires, a review of literature and focus group discussions with stakeholders.<sup>26,34</sup>

In order to construct a survey instrument, questions on key indicators contained in the National Quality Framework Responsible Care for the sector of nursing, care and homecare<sup>†</sup> were selected from existing validated questionnaires on the quality of care and quality of life of residents and the CAHPS Nursing Home Survey.<sup>32, 35, 36</sup>

The response options for frequency items are focused on a four-point scale (never, sometimes, usually and always), while general ratings of the quality of care are based on a scale of 0-10, with a score of 10 indicating the best possible score. As mentioned earlier, visual aids or answering cards were encouraged to support residents in conveying their responses during the interview process.

Prior to the implementation of the survey, draft questionnaires and protocols for sampling and data collection were tested in a pilot study with a sample of representative settings. Revisions were made to the process as required following consultation.

### The sample

The survey sampled involved all residents in nursing or long-term care homes in the Netherlands. It was decided that the sample of participants would be selected in cooperation with nursing staff from care provider organisations as they were most knowledgeable about the health and residential status of the residents. In the event of a resident being deemed unable to take part, the care provider identified the resident's key representative and a postal survey was issued to that individual instead.

---

<sup>†</sup> 10 quality domains were set out under the Framework and each domain has an associated set of indicators developed on the basis of the structure-process-outcome concept. The indicators provide a picture of what users find important and also what their experience with care is.<sup>36</sup>

With the support of a pilot study, a number of exclusion criteria were agreed prior to the study in order to promote homogeneity across study samples within the care settings and to reduce the likelihood of the survey being presented to severely ill residents or those who experienced severe cognitive impairments, for example.

The following exclusion criteria were applied as part of the implementation of the CQ-Index Long Term Care Survey:

- residents who were admitted to a centre less than a month prior to the commencement of the survey
- residents with severe cognitive or psychiatric problems
- residents were deemed very ill, of very poor health status or in a terminal phase of illness
- individuals who were present in the long-term care facility for rehabilitation or reactivation purposes only.

Pre-selection of eligible residents was typically conducted by the care provider organisations in line with a set of defined guidelines to ensure a fair sampling process was conducted across all participating centres. Providers were advised against being too restrictive in their evaluations of residents' cognitive abilities and, if in doubt, to include the person in the list. To further support this process, at the beginning of each interview, there was an opportunity for the interviewer to conduct a brief cognitive assessment of the resident and a note was placed on the survey to indicate whether the survey progressed or if it ceased at the screening stage.

In the event of a resident being unable to participate in the face-to-face interview, a family member was invited to take part in the sample on their behalf; a postal questionnaire was issued to the appointed person.

### Distribution and data collection

Certified survey vendors who are authorised to conduct CQ-Index research coordinated the survey on behalf of the care provider organisation once every two years.<sup>30</sup> The use of an independent entity promoted a more balanced and unbiased approach to data collection and analysis, in addition to ensuring the process conformed to national guidelines.<sup>30</sup> The certified organisation is also responsible for submitting data collected to a central database to enable nationwide comparisons, benchmarking and public reporting.

Due to a diverse population and various care settings, two versions of the CQ-Index questionnaire were designed, supported by specific survey methods.

The first questionnaire was designed for face-to-face interviews with residents of nursing or residential care homes who were less likely to complete lengthy questionnaire due to illness or disability.

The survey instrument for structured face-to-face interviews was designed to take approximately 45 minutes to undertake. In order to reduce the risk of bias due to interviewer-effects, it was recommended during the pilot phase that the use of answering cards is incorporated into the interview component.

The second questionnaire used a postal survey which was administered to representatives of residents (usually family members or friends) if the resident was unable to take part in a structured interview due to cognitive impairments.

Regardless of the mode of administration used to collect data, a detailed set of protocols was developed to promote a standardised approach to data collection and procedures to follow when conducting interviews and the administration of postal questionnaires.

### Communication and publicity

Residents and their representatives were informed about the survey by participating nursing homes and also through formal communication channels from the survey vendor.

Questionnaires issued to family members or friends were issued by post, along with cover information about the survey and instructions on how to complete it. A prepaid envelope which was returned to the research survey organisation was also included to increase response rates.

In addition to the initial survey pack, a total of two reminder packs which comprised of a thank you card after two weeks and a reminder letter with an additional questionnaire in week five (where relevant, in cases of non-response). A unique identification number allowed the survey team to identify non-responders and non-response analyses.

A dedicated helpdesk was also established as a communication forum to assist participants and answer questions about the survey. This facility was provided via phone call and email channels.

### 4.6 Outputs and impact of the survey

The certified survey vendor was responsible for producing a report for the care provider organisation using the survey data collected from the residents. The results were also uploaded to a national databank, where it was corrected for case-mix variables such as age, health status and the level of required care. Survey findings were then published in report format on the government website for public viewing.

The use of the CQ-Index Long-term Care Survey was required as part of reimbursement policies through which a long-term care organisation received payment for the care provided; the costs of long-term care in the Netherlands are

issued through collective financing of healthcare. As such, long-term care provider organisations were required to perform a CQ-Index measurement once every two years and if scores were below the required level, a deduction of a certain percentage from the cost to be reimbursed was imposed.

### Impact

In terms of direct impact on quality improvement, it was noted that organisations which systematically included resident experiences in their quality system were more likely to use the data for quality improvement. In other organisations, the survey data was used less systematically, and implementation of quality improvement initiatives varied somewhat. A study which examined how the long-term care surveys were being used in a practical sense identified variation across centres in the use of findings. It found that a number of organisations embraced the survey with staff creating time for residents on an individual basis, while others changed the delivery of food methods to increase enjoyment at mealtimes.

However, the study concluded that there is a clear need for the development of guidance on the effective improvement of resident experiences in this area to ensure care experience data is used in a systematic and effective manner.

### **4.7 Recommendations and lessons learned from the Netherlands**

Initially long-term care residential facilities were obliged to conduct the survey as part of the accreditation status; however, this particular survey is no longer used for the mandatory reporting of resident experiences. Of note, the instrument is still used in a self-directed capacity by some long-term care organisations, primarily to improve the quality of care and to achieve compliance with national standards.

The development of a new survey instrument within long-term care in the Netherlands has commenced but at the time of this review was still in development and not available in the public domain.

It is expected that this instrument will be administered in the form of a digital questionnaire (an app-based survey) which feeds into a real-time dashboard. It will be aligned with a broader quality cycle to continuously improve the quality of care provided in long-term care facilities.

Careful consideration around the prevalence of cognitive impairment among residents in long-term care facilities was also recommended by key personnel involved in the development of this survey instrument. Structured face-to-face interviews were recommended as the most appropriate mode of survey administration for long-term residents as it was highly unlikely that they would be able to complete a lengthy postal questionnaire due to illness, disability or some degree of cognitive impairment.

## 5. United States of America

The following review is a review of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Nursing Home Survey; a validated survey which was created for use in long-term residential care facilities in the United States of America.

### 5.1 Background

In the United States, there are approximately 15,600 nursing homes with 1.7 million registered beds providing care to 1.4 million residents.<sup>37</sup>

The CAHPS Programme is a federal initiative, sponsored by the Department of Health and Human Services in the United States, which was established to measure people's experiences of healthcare.<sup>38</sup> As part of this programme, the CAHPS Nursing Home Survey was developed specifically to measure residents' experiences with the quality of care provided in nursing homes.<sup>39</sup> The development of the survey was jointly supported by the Centers for Medicare and Medicaid Services (CMS), which has responsibility for the oversight of nursing home quality, and the Agency for Healthcare Research and Quality.<sup>39</sup>

The perspective of service users has become a key measure of the quality of care provided to individuals in the United States, alongside the more traditional clinical measures.<sup>40</sup> In the context of nursing home provision however, it is unique in that quality of care is intermingled with quality of life due to the type of setting involved; nursing home residents live in the same place as the one where they receive their care.<sup>40</sup>

### 5.2 Objectives

The CAHPS Nursing Home Survey was designed to:

- measure and evaluate the experiences of individuals in residential care
- learn about the care that nursing home residents receive in a nursing home
- improve the quality of care in nursing homes
- provide comparable data on care experiences to enable meaningful comparisons across nursing homes on the aspects of care that are important to residents.

The survey aimed to meet the needs of a diverse cohort of individuals within nursing home settings. As such, the CAHPS Nursing Home Survey comprises three standardised survey instruments which were designed to capture information on the experiences of nursing home residents and their family members.<sup>39</sup>

Each of the instruments outlined below, was designed to meet different requirements within a nursing home setting:

- **Long-Stay Resident Survey:** an in-person structured interview designed to ask long-term residents about their experiences of the nursing home
- **Discharged Resident Survey (short-stay):** a postal questionnaire designed to ask recently discharged, short-stay residents about their experiences of care
- **Family Member Survey:** a postal questionnaire designed to ask family members about their experiences with the nursing home.

In the 2007 to 2008 period, a proposal was made by the Centers for Medicaid and Medicare Services (CMS) to use the findings of care experience surveys to inform the development of payment and reimbursement policies for residential care providers in the United States; the idea was that receipt of payment would be partly based on scores received through the publicly available care experience reports.

### **5.3 Governance arrangements**

The CAHPS Nursing Home Survey is part of the wider Consumer Assessment of Healthcare Providers and Systems family of surveys. CAHPS is a registered trademark of the Agency for Healthcare Research and Quality.<sup>38,39</sup>

The CMS is a federal agency operating within the Department of Health and Human Services which has responsibility for the oversight of nursing home quality in the United States. This agency jointly developed the CAHPS Nursing Home Survey to measure the care experiences of residents in nursing homes to improve the quality of care received.

The Agency for Healthcare Research and Quality (AHRQ) is the lead federal agency responsible for improving the quality and safety of the health care system in the United States. It works to drive excellence in healthcare by producing evidence to make healthcare safer, more accessible, higher quality, equitable and affordable. AHRQ jointly supported the CMS in the development of the CAHPS Nursing Home Survey.<sup>41</sup>

### **5.4 Data protection and consent**

The CAHPS Nursing Home Survey obtained personal information on residents from each nursing home in order to administer the survey and obtain key insights into the lived experiences of residents. All personal information was kept strictly private and was not shared with anybody without the person's prior consent and responses to the survey were also kept confidential.

Participation in the survey was voluntary. Residents and family members were informed that, should they choose to decline the invitation to participate or withdraw from the process at any time, the care provided by the nursing home would not be affected in any way.

As part of the long-term resident survey interview, participants were asked from the outset if they consented to participate and their answer was recorded on the first page of the interview booklet. If the person agreed to take part, the interview could proceed, once a private location was available to maintain confidentiality and align with data protection guidance. Participants were told that they could skip questions and stop participating at any time; in such situations, the interview was halted immediately, a note was made on the survey, and the person was informed that this decision would not affect their care.

For individuals who received a postal survey, the same information was clearly provided to them in terms of consent and data protection. In addition, an identification number was used on the cover of each postal survey simply to inform survey vendors if the person had returned the survey in order to avoid issuing reminders.

## **5.5 The survey**

The CAHPS Nursing Home Survey was developed in line with extensive stakeholder engagement and piloting of survey instruments. Common themes appeared during engagement with residents, including the importance of communication between the care provider and resident, access to care and treatment and the preferences expressed by residents in terms of the type of care provided to them.

The key steps followed in the development of the project include:

- a literature review
- engagement with experts, nursing home providers, advocacy organisations.
- focus groups with residents and family members (using trained moderators).
- cognitive testing of survey questions with nursing home residents
- field testing of the questionnaire with residents from a sample of nursing homes, followed by revisions and amendments to the instrument.

The Long-Term Resident Questionnaire is available in English and Spanish. The survey contains a total of 45 questions is designed to be administered using a face-to-face interview which takes approximately 20 minutes to complete.

The questionnaire contains survey items which reflect food and mealtimes, physical environment, support from staff, care provided by staff, feelings of happiness or worry, activities, medication, privacy, independence and overall ratings of care. There are a number of demographic information questions included also.

The Discharged Resident Questionnaire is also available in English and Spanish and is almost identical in content to the long-term resident version. The key difference being that this instrument also covered therapy services and the person's transition out of the nursing home. It contained a total of 50 survey questions. It is designed to be administered as a postal survey.

Both survey instruments ask respondents about the quality of care received in the nursing home and also about their quality of life. The quality of care questions generally use a 0–10 rating scale, while the quality of life questions tend to follow a 'yes/no/sometimes' response format.

At a general level, both resident instruments cover the following topic areas:

- environment
- care
- communication and respect
- autonomy
- activities.

The Nursing Home Family Member Survey is also available in English and Spanish. It comprised of 51 questions and is designed to be administered as a postal survey.

The family member questionnaire includes the following topic areas:

- about the nursing home resident
- the family member's visits to the nursing home
- the family member's experiences with nurses and aides
- the nursing home (staffing, environment, respect and so on)
- care of the family member by the nursing home
- the family member's overall experience of the nursing home.

### The sample

Due to the diversity and differing cognitive abilities of residents in nursing homes, it was important that the survey met the needs and requirements of the target population of nursing home residents. The survey population was therefore divided into three sub-groups; long-term residents, discharged residents and family member representatives. Family member representatives were also included as an entity within the sample population and were surveyed independently of residents.

It was decided to separate the views of residents and family members as they are likely to hold different perspectives on the type and quality of care received.<sup>40</sup> Discrepancies have been demonstrated in other studies between proxy respondents (family members or staff) and residents.<sup>42</sup>



The Family Member Survey therefore complements the residents' survey and contributes to a broader understanding of the care provided in nursing homes.

### Distribution and collection of data

Certified survey vendors were normally employed to administer and coordinate data collection as part of the CAHPS Survey Programme on behalf of the long-term care organisation; this arrangement ensures that data collection is consistent with the recommended CAHPS protocols for survey administration, reduces the administrative burden on care providers and also ensures neutrality of results by reducing potential sources of bias. Nursing homes were asked to establish a contract with certified survey vendors and to provide the relevant contact information to the vendor to facilitate survey administration.

Within the CAHPS Nursing Home Survey, there were three instruments developed in order to meet the needs of the target population:

**Long-Stay Resident Survey:** administered to residents who were currently living in nursing homes for more than 100 days.

**Discharged Resident Survey:** administered to residents recently discharged from nursing homes after a short stay of no more than 100 days.

**Family Member Survey:** administered to family members in order to report on their own experience (not the resident's) with the nursing home and their perceptions of the quality of care provided to a family member living in the nursing home.

The CAHPS Long-Term Care questionnaire was designed to be administered using face-to-face structured interviews. This approach was selected on the basis that the 'voice of the resident' is considered to be the gold standard, with due consideration given to the prevalence of cognitive impairment in this population.<sup>43</sup> As such, a cognitive screening tool was used at the beginning of the interview to ascertain whether a resident would be able, and feel comfortable, to participate. Visual aids, referred to as showcards, were used throughout the interview to support the respondents; for example, one showcard contained a number of response options (Yes, No, Sometimes), while another showcard focused on a scale of 1–10.

The Discharged Resident Surveys and Family Member Surveys were designed to be administered by post with an option to respond to the survey by return post or else by telephone. No other modes of administration are used for these surveys.

## Communication and publicity

Long-term nursing home residents were informed of the face-to-face interview in advance and were told about its purpose and how they could participate. Prior to the interview, the trained interviewer took the time to talk to the resident in order to introduce themselves and introduce the survey.

The first point of contact for recently discharged residents and family members of residents with the CAHPS Nursing Home Survey was receipt of the survey pack which comprised of a letter of invitation, the questionnaire and a prepaid envelope addressed to the survey vendor. Instructions on how to complete the survey were also included along with the purpose of the survey.

### **5.6 Outputs and impact of the survey**

The CAHPS Nursing Home Survey reports were developed for the public to provide information on the performance of nursing homes and identify particular centres that meet their needs. The objective of reports intended for nursing home providers and managers comprised of more detailed information to support the use of the results to identify areas of good practice and areas needing improvement. These reports presented trend data (if available), results at item-level detail and sets of comparator data such as local or state averages or percentiles.

Survey data was arranged in a way to support analysis using SAS software and a collection of SAS files that comprise the CAHPS Analysis Programme; this programme allows the required analysis and statistical adjustments within the survey data in order to make valid comparisons among different provider organisations.

#### Impact

It is important to note that the CAHPS Nursing Home Survey was not widely implemented, as originally expected, in the US due to a number of factors including the administrative and financial burden that this particular approach carries. Therefore, the public availability of reports and survey findings is limited as is the impact of the programme on care provision in nursing homes.

### **5.7 Recommendations and lessons learned from the United States**

While the research methodology underpinning the CAHPS Nursing Home Survey was rigorous and of high quality, the programme was not widely implemented across facilities as initially expected. This was primarily due to the associated costs and administrative burden, as well as challenges in developing a standardised approach to align with the diversity of care delivered in some facilities in the US.

The development process demonstrated the importance of cognitive interviewing to test survey items with a representative sample of participants prior to full-scale implementation – this is particularly relevant in the context of nursing home residents and the potential for a high prevalence of cognitive impairment.

The testing in this instance supported the team in understanding the most appropriate wording for survey items, providing insights on question types and formats, time periods and response tasks.

Questions which were based on ratings of care were found to be more useful than questions which asked participants to summarise their experience across place and time, due to the difficulties that level of cognitive recall would require. It was recommended that surveys of nursing home residents use the non-specific present rather than explicit time periods. Questions which used the 0-10 scale were also well received by participants which is consistent with other studies involving older people<sup>44</sup>, while a response scale (yes/sometimes/no) was also found to be helpful.

## 6. Canada

The following is a review of the Every Voice Counts: Residential Care Survey; the most extensive survey of its kind undertaken in Canada, conducted across residential care facilities in British Columbia.

### 6.1 Background

There are many different types of survey tools in use across long-term care facilities in Canada which capture the experiences of residents in terms of the quality of care received. It is well-recognised that care experience indicators allow residents to become partners in their own healthcare and providing a way for authorities to assess whether care is truly resident centred.

The Canadian Institute for Health Information (CIHI) believes that the use of a standardised survey tool which facilitates pan-Canadian comparisons and benchmarking is key to improving the performance of care providers and key standards of care.<sup>45</sup> CIHI is currently working with various jurisdictions across Canada to identify and understand the need to measure the continuum of care, beginning with resident experience in long-term care.<sup>46</sup> Researchers are planning to build on the work which was undertaken to develop the Canadian Patient Experiences Survey on Inpatient Care in order to identify a similar questionnaire relevant for long-term care reporting.<sup>47</sup>

Collaborative work is underway between CIHI and a team of partners to identify a single, common survey tool to be used in long-term care facilities across Canada.<sup>46</sup> It is expected that the implementation of such an initiative would be linked with long-term care centre accreditation status in time and become a mandatory requirement of the accreditation process.<sup>46</sup> The Inter-Jurisdictional Working Group on Patient Satisfaction for Long-Term Care is a collaborative group of decision-makers which is working to share best practice in the selection and implementation of patient and resident experience surveys. As part of their work, the group has identified a number of surveys in use across long-term care facilities in Canada. The most widely used, tested and validated survey used in Canada to understand the experiences of individuals living in residential care is the InterRAI Self-Reported Resident Quality of Life Survey for Long-Term Care Facilities, which is also endorsed by the Canadian Institute for Health Information (CIHI).<sup>46</sup>

One of the most extensive surveys of its kind in Canada used and adapted this particular survey to capture the care experiences of residents in long-term care facilities.

The Every Voice Counts: Residential Care Survey involved a target population of over 22,000 residents across 292 centres in British Columbia and their most frequent visitor. The survey was conducted between September 2016 and September 2017.<sup>48</sup>

## **6.2 Objectives**

The Every Voice Counts: Residential Care Survey was implemented to provide an opportunity for residents to share their experiences of living in residential care and all long-term care centres in British Columbia. It was also intended to drive the performance of the long-term residential care sector in British Columbia, enhance public accountability and provide a roadmap to support quality improvement.<sup>49</sup>

## **6.3 Governance arrangements**

Five health authorities in British Columbia provide residential care services to primarily frail older adults through both health authority owned and operated locations as well as contracted care facilities operating as either for profit or not for profit.

The Office of the Seniors Advocate has a statutory obligation to monitor the services provided to older people, including residential care settings, and to publicly report on their work.<sup>50</sup> As part of this work, a commitment was made to undertake a survey of all residents in all publicly-funded care facilities across the province to ask about their experiences of living in residential care to find out what was working well and also to identify areas for improvement. It was also agreed to ask the opinion of their family members.

The Ministry of Health provided the funding for this initiative while the British Columbia Office of Patient-Centred Measurement was involved in conducting the survey on behalf of the Ministry of Health.<sup>51</sup>

## **6.4 Data protection and consent**

The information collected on residents from each facility and provided to the survey vendor was used for the purposes of conducting the survey; the information included personal information, room and bed number. The information components which were used, disclosed and retained in order to undertake Patient Experience of Care Surveys are statistical in their properties, meaning the results cannot be used to influence the treatment of participating residents.

The British Columbia Freedom of Information and Protection of Privacy Act serves to protect the personal privacy of citizens by prohibiting the unauthorised collection, use or disclosure of personal information by public bodies.<sup>52</sup>

The survey vendor, who was responsible for coordinating the survey process on behalf of each centre, was required to demonstrate compliance with the Act. In addition, a privacy impact assessment (PIA) was completed and approved by the Health Information and Privacy Operations Committee of British Columbia. An on-site audit of the survey vendor's operations was conducted to review the way in which personal health information of residents was managed.<sup>53,54</sup>

Furthermore, in order to comply with the Act, survey vendors were required to fulfil obligations related to a notification regime outlined by the legislation. As such, signs were posted in each participating centre to inform residents that they may be invited to participate in a survey. These notification posters also included information on the 'opt-out' process and the use and protection of personal information.<sup>53</sup> Residents were then approached up to three times for consent to participate in the survey.

## 6.5 The survey

The Every Voice Counts: Residential Care Survey selected the InterRAI Self-Reported Resident Quality of Life Survey for Long-Term Care Facilities as the basis through which to capture survey data on resident experience; it is the most widely used, tested and validated tool in Canada through which to understand the care experience of residents in long-term residential care.<sup>53</sup> The survey tool is endorsed by the Canadian Institute for Health Information (CIHI) for standardised pan-Canadian resident-centred measurement.<sup>45,46</sup> It is a licensed survey tool which incurs an authorisation fee and carries certain terms and conditions, including procedures around data collection materials.

In addition to the core questions selected from the InterRAI tools, extra questions on medication use, physician care, handwashing and other topics to further evaluate their care experience were included in the questionnaire. The questions were tailored to suit the context of the Every Voice Counts initiative and were also relevant to align with the provision of long-term care in British Columbia. Furthermore, the development and implementation of this particular survey was the first time that information from Patient-Reported Experience Measures (PREMs) has been collected in a simultaneous manner with and Patient-Reported Outcome Measures (PROMs) in long-term residential care.<sup>53</sup>

All customised questions were cognitively tested in advance of survey implementation and were primarily grouped as follows in the final instrument:

- PREMs-related questions<sup>54</sup>, including:
  - including topics such as food, security, activities, comfort, environment, privacy, respect, autonomy, staff responsiveness and overall experience.
- PROMs-related questions<sup>54</sup>, including:
  - including topics such as physical health, mental health, overall health status, social functioning, physical functioning, perceived health status and energy-fatigue.
- Demographic information questions.

In addition to the quantitative component, open-ended questions were included at the end of each page to record open text comments related to the particular page topic during the interview. Residents and most frequent visitors alike were also invited to respond to a question at the end of the survey which asked 'is there anything else you would like to tell us about your experience living here?'.<sup>54</sup>

Following a rigorous process, a dedicated resident instrument, comprised of 103 questions, was agreed and developed for implementation. It was designed to be administered using structured face-to-face interviews with residents.<sup>48,53</sup>

In addition, the interRAI Family Survey for Long Term Care was developed as a separate accompaniment to the resident survey and administered to residents' most frequent visitor (normally a family member or friend). Questions on this survey were almost identical to those contained on the resident survey. The aim of the family survey was to understand their experience from the perspective of the person's most frequent visitor and the items on this survey were almost identical to those on the resident survey. This survey comprised of 104 questions, including specific questions on overall quality or experience of care. It was designed to be administered by post with an option to respond by return post to the survey organisation or else through an online platform.<sup>53</sup>

### The sample

In an effort to ensure that 'every voice counts', a census of residents in long-term care was obtained. All eligible residents and their most frequent visitor in one of British Columbia's 292 facilities were invited to take part in the survey. The total population invited to participate was 22,162, along with 21,334 most frequent visitors. The survey was completed by 9,812 residents and 10,049 most frequent visitors of residents as a matched sample.

In order to obtain data on residents and their most frequent visitors, health authority representatives compiled the required contact data and submitted the records of all eligible residents in participating long-term care facilities to the survey vendor. A data file submission manual was developed to support the process. The survey vendor then created a list of all eligible residents and survey materials; once this was verified with the health authority liaison persons, the information was sent to the printing vendor for processing.

Long-term care homes with one or more publicly-funded beds were included in the survey and, where there were private paying residents co-residing in the same home as publicly-funded residents, the private pay residents were also included.

### Inclusion criteria

- Residents who lived in the facility for at least two weeks prior to the start date of the interviews.

While it was intended to survey a wide range of experiences across long-term residential care, not all residents were eligible for inclusion. The following exclusion criteria were set out:

### Exclusion criteria

- Palliative care: residents who were in a palliative or special care unit
- Deceased: residents who had passed away prior to interview periods
- Could not locate: residents who were away or not in the care home during interview times
- Risk to interviewer: residents who were deemed aggressive or unsafe to approach by an interviewer
- Discharged: residents who had been discharged prior to the commencement of interviews
- Belonging to a Special Care Unit
- Language: residents who did not speak one of the 10 languages in which the survey was available.

### Distribution and collection of data

The structured face-to-face interviews with residents were conducted by trained interviewers, independent from each centre. A standard structured interview technique was used to administer this survey and interviewers approach residents up to three times for consent to participate in order to attempt the survey.



Prior to commencing the interviews, the trained interviewers met with the facility liaison person to review the resident lists with them in order to verify residents who were eligible to be approached for interview.

To support the interview process, interviewers were issued with a set of response boards or answer cards which were used during interviews to provide residents with a visual of response options. Upon completion of an interview, the resident was marked off the resident list and the survey was placed in a sealed envelope and returned to a designated location on a daily basis. Resident responses were then entered into a secure database and collated by the vendor.

Residents' most frequent visitors also received surveys even if the resident was unable or unwilling to take part in the interview process. Each long-term care residential centre was asked to send a record level data file (containing the information needed to contact the most frequent visitor) to the survey organisation. The verified file was then processed and a cover letter with surveys were printed and posted to the address of the identified person.

Surveys expired 120 days from the date the data file was processed, with results received after that date excluded from the count and analysis of responses. It was possible to respond to the family member survey via postal return or else online.

### Communication and publicity

In order to conduct the inform residents and facilities about the survey process, a Welcome Package was compiled and issued to each participating organisation to distribute information and promote the survey. As part of the Welcome Package, specific information on the protection of personal information was provided, as well as contact information if a resident had questions or if they wished to be removed from the survey contact list.<sup>53</sup>

In addition, one month in advance of the on-site interviews, notification posters were posted in each care home in order to comply with the legislation mentioned earlier.

The purpose of these posters was primarily to inform residents and their most frequent visitors that they may be invited to participate, in addition to the time frame within which the survey would take place. Information on how to opt out of the process was also included.

Separately, as part of the administration of the surveys to residents' most frequent visitor, a survey questionnaire and a cover letter from the Office of the Seniors' Advocate was posted to the addresses provided to the survey vendor in the data file.

A reminder letter with another copy of the survey was posted to non-responders 21 days later to encourage participation rates.

### Response rate

The overall response rate for the Long-Term Care Resident Survey was 44.6% while the overall response rate for the corresponding Most Frequent Visitor Survey was 48.8%.<sup>53</sup> The response rate was calculated by dividing the number of completions over the valid sample.

## 6.6 Outputs and impact of the survey

For the duration of the survey period, and upon the close of data collection, aggregate data at facility, health authority and provincial level was provided to relevant audiences to provide interim results and a summary of final results. Reports were compiled by vendors, while the Office of the Seniors Advocate also generated a provincial report, a health authority report and facility level reports which summarise final survey results. These reports are available online.

The following techniques were used to analyse the data:

- Percent positive score: the percentage of respondents who selected any positive response category to a question on the survey, with responses normally standardised as a percentage of positive answers.<sup>53</sup>
- Dimension or theme scores: a composite score which is based on an unweighted sum of all items which comprise a given dimension or theme.<sup>53</sup>
  - the resident survey consisted of a set of questions designed to examine different dimensions of Patient-Reported Experience Measures (PREMs) and Patient-Reported Outcome Measures (PROMs).<sup>54</sup>

Responses to the open-text questions at the end of the surveys were transcribed verbatim for the resident survey and were entered exactly as written for the mail or online survey completed by most frequent visitors. Personal identifiers were masked, and each comment was then coded into predefined themes (for example, privacy, food, comfort, autonomy and so on), along with valence codes<sup>‡</sup> within each theme.<sup>53</sup>

---

<sup>‡</sup> A valence code indicates whether the theme-specific comment was positive, negative, neutral or both positive and negative.

## Impact

The Every Voice Counts: Residential Care Survey results have since informed wide-ranging quality improvement initiatives and enabled leaders and staff to hear directly from residents and their families or visitors in order to understand their priorities. Plans were made to repeat the survey in 2020/2021 for the purposes of trending results over time but, due to the impact of COVID-19, timelines have been affected.

A family survey to explore and understand the impact of visitor restrictions during the COVID-19 pandemic is currently in planning.<sup>49</sup>

### **6.7 Recommendations and lessons learned from Canada**

Close collaboration and engagement with policy-makers, accreditation bodies and a mix of care provider types, including public and private providers, was integral throughout the process of developing this survey. In relation to the implementation of the survey, it was recommended that trained interviewers who are independent from the centres are used to conduct structured interviews with residents. This is in an effort to reduce the potential bias which may arise due to the direct involvement of immediate care providers in the process.

In terms of the mode of administration used in long-term care settings, all surveys identified in the environmental scan undertaken by CIHI utilised face-to-face interviews with residents in order to capture their experiences. Postal surveys with family members were used if a resident was unable to take part in the interview.

It was recommended that the length and detail of questions contained in a survey of long-term care facilities is tailored to the target population of primarily older residents; the completion of the survey or interview should not be overly onerous, and all administrative processes should be as straightforward as possible to avoid placing undue burden on care providers. The suggested completion time of a survey in this setting is between 15-20 minutes.

Consideration also needs to be given to the prevalence of cognitive impairment within this population; the review undertaken by CIHI and its partners identified that the use of visual aids help to support residents in responding to questions. In the Every Voice Counts: Residential Care Survey in Canada, care providers were asked to provide information on residents' cognitive ability in order to inform the list of eligible residents who can take part in the survey. Should there be an expectation that the interview assesses a resident's cognitive ability, an elevated level of training and expertise is required to reduce the potential for bias to arise. It was therefore recommended to coordinate a model through which to obtain a list of eligible residents directly from the care provider.

## **7. Conclusion**

### **7.1 Findings**

The findings of this review are set out in Section 2 – Summary of Findings.

### **7.2 Next steps**

The National Care Experience Programme will use and adapt the models and methodologies outlined in this paper to inform the development of the National Nursing Home Experience Survey for Ireland.

## Appendices

### Appendix A.

Participants and organisations that contributed to this review

The National Care Experience Programme would like to thank the contributors and their organisations for providing their time, knowledge and expertise to inform this international review.

Country	Organisation	Type of organisation	Title of personnel who contributed to this review
Australia	La Trobe University	Academic	Director/Associate Professor, Australian Centre for Evidence Based Aged Care/Australian Institute for Primary Care and Ageing, La Trobe University. Professor of Aged Care Research and Policy Development/Head, Lincoln Centre for Research on Ageing, La Trobe University.
The Netherlands	Netherlands Institute for Health Services Research.	Independent research institute	Senior Researcher, Netherlands Institute for Health Services Research. Professor, Erasmus School of Health Policy & Management Health Care Governance/Centre for Consumer Experience in Healthcare
United States of America	Agency for Healthcare Research and Quality Westat	Government agency Research service	Director, CAHPS and Surveys on Patient Safety Culture Programmes, AHRQ. Senior Study Director, Westat. CAHPS Technical Assistance Liaison, Westat.
Canada	Canadian Institute for Health Information	Government agency	Project Specialist (Specialised Care) and Manager (Specialised Care Development.)

## Appendix B

Summary table of the reviewed models and methodologies used to implement a survey of nursing home residents internationally

Country	Purpose of survey	Population	Survey tool	Mode of administration	Outputs
<b>Australia</b>	To provide information about residents' experiences of the quality of care received in aged care services in Australia.	A minimum sample of 10-12% of residents from each centre during accreditation site audits of residential aged care services	A 12—item questionnaire: based on the Australian Residential Aged Care Standards and the key domains of quality and care.	Face to face structured interviews with residents, conducted by auditors during mandatory accreditation audits.	Publicly available reports published on The Commission's website; to inform quality improvement in residential services.
<b>The Netherlands</b>	To provide information on individuals' experiences of nursing homes, inform quality improvement.	Residents in long-term care homes, pre-selected by care provider organisations in accordance with guidelines.	A 29-item survey for residents and a 35-item survey for their representatives.	Face-to-face interviews with a sample of residents; Postal questionnaires for representatives of residents	Compulsory publication of performance reports; reports used to inform the quality of service provision.
<b>United States</b>	To measure and evaluate the experiences of individuals in residential care to improve the quality of care provided.	Residents of nursing homes in the United States and their designated representatives.	Three survey instruments were developed ranging from 45 to 51 item questionnaires,	Structured interviews for long-term residents. Postal questionnaire for discharged residents and for representatives.	Publicly and privately accessible reports were outlined as outputs for this survey but the survey was not widely implemented and so reports are limited.
<b>Canada</b>	To provide an opportunity for residents to share their experiences of living in residential care.	Residents in publicly-funded long-term residential care homes in British Columbia and their most frequent visitor	Adaptation of the interRAI Self-Reported Resident Survey for Long Term Care Facilities (103 items) and InterRAI Family Survey	In-person interviews with resident and a postal questionnaire for a resident's most frequent visitor.	Detailed survey results published at provincial level, along with tabulated results at health authority and facility-level.

## References

1. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press, 2001.
2. Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T. Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care. San Francisco: Jossey-Bass, 1993.
3. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press, 2001.
4. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open 2013.
5. Coulter A, Fitzpatrick R, Cornwell J. The point of care - Measures of patients' experience in hospital: purpose, methods and uses. The King's Fund, 2009.
6. Luxford K, Sutton S. How does patient experience fit into the overall healthcare picture? Patient Experience Journal. 2014;1(Inaugural issue).
7. Department of Health. Statement of Strategy 2016-2019. <https://health.gov.ie/wp-content/uploads/2016/12/DoH-SoS-2016-2019-Final-En.pdf>
8. Department of Health. Creating a better future together. The National Maternity Strategy, 2016-2026 <https://health.gov.ie/wp-content/uploads/2016/01/Final-version-27.01.16.pdf>
9. Department of Health. The National Cancer Strategy, 2017-2026 Available at: <https://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf>
10. Department of Health. Sláintecare Implementation Strategy. Available at: <https://health.gov.ie/wp-content/uploads/2018/08/Sl%C3%A1intecare-ImplementationStrategy-FINAL.pdf>
11. National Care Experience Programme, National Inpatient Experience Survey 2017. Available at: <https://www.patientexperience.ie/app/uploads/2018/02/NPES-National-Report-2017- WEB.pdf>

12. HSE Listening, Responding and Improving. The HSE response to the findings of the National Patient Experience Survey 2018. Available at:  
[https://www.patientexperience.ie/app/uploads/2018/11/NPES\\_National\\_QIP\\_2018.pdf](https://www.patientexperience.ie/app/uploads/2018/11/NPES_National_QIP_2018.pdf)
13. National Care Experience Programme. Strategic Plan 2019-2021. Available at:  
<https://yourexperience.ie/wp-content/uploads/2019/07/NCEP-Strategic-Plan-2019-2021-2.pdf>
14. COVID-19 Nursing Homes Expert Panel: Final Report. Available at:  
<https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>
15. Aged Care Quality and Safety Commission. About the Commission. Available at:  
<https://www.agedcarequality.gov.au/about-us>
16. Aged Care Quality and Safety Commission. About aged care in Australia. Available at: <https://www.health.gov.au/health-topics/aged-care/about-aged-care>
17. Aged Care Quality and Safety Commission. Aged Care Quality Standards. Available at: <https://www.agedcarequality.gov.au/providers/standards>
18. Aged Care Quality and Safety Commission. Consumer Experience Reports in Residential Aged Care Services. Available at:  
<https://www.agedcarequality.gov.au/consumers/consumer-experience-reports-residential-aged-care-services>
19. Wells Y, Herd A & Fetherstonhaugh D 2017. Developing a consumer experience report: pilot stage. Melbourne: Australian Institute for Primary Care & Ageing, La Trobe University.  
[https://www.agedcarequality.gov.au/sites/default/files/media/pilot\\_study\\_la\\_trobe\\_university\\_consumer\\_experience\\_reporting\\_final\\_pdf.pdf](https://www.agedcarequality.gov.au/sites/default/files/media/pilot_study_la_trobe_university_consumer_experience_reporting_final_pdf.pdf)
20. University of Sydney. Quality domains for the development of a consumer experience report on quality of residential aged care: a rapid review to the Australian Aged Care Agency. Available at:  
[https://www.agedcarequality.gov.au/sites/default/files/media/drivers\\_of\\_choice\\_and\\_quality\\_domains\\_in\\_aged\\_care\\_pdf.pdf](https://www.agedcarequality.gov.au/sites/default/files/media/drivers_of_choice_and_quality_domains_in_aged_care_pdf.pdf)
21. Aged Care Quality and Safety Commission. A voice and choice in quality care brochure; resident experience reports – an information leaflet Available at:  
<https://www.agedcarequality.gov.au/sites/default/files/media/CER%20Residential%20Care%20Brochure.pdf>



22. Australian Institute of Health and Welfare. Consumers' experience of residential aged care Australia 2017–19. Available at: <https://www.aihw.gov.au/getmedia/87fa8d3e-ca23-48e7-905f-57df367f8f14/aihw-age-101.pdf.aspx?inline=true>
23. La Trobe University. Analysis of consumer experience report (CER) data: Report to the Australian Aged Care Quality Agency, December 2018. Available at: [https://www.agedcarequality.gov.au/sites/default/files/media/la\\_trobe\\_analysis\\_of\\_consumer\\_data.pdf](https://www.agedcarequality.gov.au/sites/default/files/media/la_trobe_analysis_of_consumer_data.pdf)
24. Australian Institute of Health and Welfare. Consumers' experience of residential aged care Australia 2017–19. Available at: <https://www.aihw.gov.au/getmedia/87fa8d3e-ca23-48e7-905f-57df367f8f14/aihw-age-101.pdf.aspx?inline=true>
25. Sixma HJ, Kerssens JJ, Van Campen C, Peters L. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. *Health Expectations* 1998; 1(2): 82-95
26. Triemstra, M., Winters, S., Kool, R.B. et al. Measuring client experiences in long-term care in the Netherlands: a pilot study with the Consumer Quality Index Long-term Care. *BMC Health Serv Res.* 2010.
27. Damman O. Public reporting about healthcare users' experiences: the Consumer Quality Index: Netherlands Institute for Health Services Research. *J Stroke Cerebrovasc Dis.* 2010.
28. Delnoij, D.M., Rademakers, J.J. & Groenewegen, P.P. The Dutch Consumer Quality Index: an example of stakeholder involvement in indicator development. *BMC Health Serv Res.* 2010.
29. Sixma HJ, Delnoij DMJ, (eds): [CQI Manual. An instruction for the development and use of Consumer Quality Index (CQI) questionnaires]. 2007, Utrecht: Centrum Klantervaring Zorg
30. Marloes Zuidgeest, Mathilde Strating, Katrien Luijkx, Gert Westert, En Diana Delnoij, Using client experiences for quality improvement in long-term care organizations, *International Journal for Quality in Health Care*, Volume 24, Issue 3, June 2012, Pages 224–229, <https://doi.org/10.1093/intqhc/mzs013>
31. Cosenza C, Fowler FJ, Buchanan JL, Cleary PD, Ding L: Nursing Home CAHPS Field Test Report. 2006, Boston: University of Massachusetts, Harvard Medical School
32. CAHPS Nursing Home Survey – Long Stay Resident Survey Instrument. Available at: [https://www.cahps.ahrq.gov/content/products/nh/NH\\_Long-Stay\\_Instrument.pdf](https://www.cahps.ahrq.gov/content/products/nh/NH_Long-Stay_Instrument.pdf)

33. Sixma HJ, Van Campen C, Kerssens JJ, Peters L: Quality of care from the perspective of elderly people: the QUOTE-elderly instrument. *Age Ageing*. 2000, 29 (2): 173-178. 10.1093/ageing/29.2.173.
34. Delnoij, D.M., Rademakers, J.J. & Groenewegen, P.P. The Dutch Consumer Quality Index: an example of stakeholder involvement in indicator development. *BMC Health Serv Res*. 2010.
35. ActiZ. A Quality Framework for Responsible Care in the Netherlands: long-term care facilities. [https://static-content.springer.com/esm/art%3A10.1186%2F1472-6963-10-95/MediaObjects/12913\\_2009\\_1232\\_MOESM1\\_ESM.PDF](https://static-content.springer.com/esm/art%3A10.1186%2F1472-6963-10-95/MediaObjects/12913_2009_1232_MOESM1_ESM.PDF)
36. Van der Veen, R. and S. Mak (2010), "Developing and Ensuring Quality in Long-term Care: Netherlands National Report", InterLINKS, September, Utrecht.
37. The Centers for Disease Control and Prevention. Nursing Home Care in the United States. Available at: <https://www.cdc.gov/nchs/fastats/nursing-home-care.htm>
38. Agency for Healthcare Research and Quality. CAHPS Survey Programme. Available at: <https://www.ahrq.gov/cahps/index.html>
39. Sangl J, Buchanan J, Cosenza C, Bernard S, Keller S, Mitchell N, Brown J, Castle N, Sekscenski E, Larwood D. The development of a CAHPS instrument for Nursing Home Residents (NHCAHPS). *J Aging Soc Policy*. 2007;19(2):63-82.
40. CAHPS Nursing Home Surveys. Agency for Healthcare Research and Quality, Rockville, MD. Available at: <https://www.ahrq.gov/cahps/surveys-guidance/nh/index.html>
41. Agency for Healthcare Research and Quality. About AHRQ. Content last reviewed November 2017. Available from: <https://www.ahrq.gov/cpi/about/index.html>
42. Kane, R. A., Kane, R. L., Giles, K., Lawton, M. P., Bershadsky, B., Degenholtz, H., Kling, K., Cutler, L., & Grant, L. First Findings from Wave 1 Data Collection: Measures, Indicators, and Improvement of Quality of Life in Nursing Homes. Report to CMS, Prepared under Master Contract #500-96-0008. 2020.
43. Kane, R. A., Kling, K., Bershadsky, B., & Kane, R. L. Quality of life measures for nursing home residents. *Journal of Gerontology: Medical Sciences*, 58A, M240-M2484. 2003.
44. Castle, N. & Engberg, J. Response formats and satisfaction surveys for elders. *The Gerontologist*. 2004: 44(3).

45. Canadian Institute for Health Information. About the Institute. Available from:  
<https://www.cihi.ca/en>

46. Canadian Institute for Health Information. Patient reported experiences measures. [https://www.cihi.ca/sites/default/files/patient\\_reportedexpmeasuresltc-en\\_web\\_1.pdf](https://www.cihi.ca/sites/default/files/patient_reportedexpmeasuresltc-en_web_1.pdf)

47. Canadian Institute for Health Information. About the Canadian patient experience survey on inpatient care. <https://www.cihi.ca/en/patient-experience/about-the-canadian-patient-experiences-survey-on-inpatient-care>

48. Office of the Seniors Advocate, British Columbia. Every Voice Counts: Residential Care Survey Provincial Results and Programme Overview.  
<https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2017/09/Provincial-Results-Final-HQ.pdf>

49. Every Voice Counts: Residential Care Survey overview. Available from  
<https://surveybcseniors.org/about/>

50. Office of the Seniors Advocate, British Columbia. Available from:  
<https://www.seniorsadvocatebc.ca/about-us/>

51. British Columbia Patient Centred Measurement Steering Committee. Patient Centred Measurement. Available from: <https://www.bcpcm.ca/surveys>

52. British Columbia Freedom of Information and Protection of Privacy Act. Available at: [https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96165\\_00](https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96165_00)

53. The BC Patient Centred Measurement Steering Committee. OSA Long-term Residential Care Facility Survey 2016/17. Healthideas Toolkit for Data Users Available at:  
[https://www.popdata.bc.ca/sites/default/files/documents/data/PCM/OSA%20LTC%20Survey%20\(2016\\_17\)%20HealthIDEAS%20Toolkit%2020201118%20Final.pdf](https://www.popdata.bc.ca/sites/default/files/documents/data/PCM/OSA%20LTC%20Survey%20(2016_17)%20HealthIDEAS%20Toolkit%2020201118%20Final.pdf)

54. The BC Patient Centred Measurement Steering Committee. OSA Long-Term Residential Care Facility Survey 2016/2017. Data User Guide. 2020. Available at:  
[https://www.popdata.bc.ca/sites/default/files/documents/data/PCM/OSA%20LTC%20Survey%20\(2016\\_17\)%20Data%20User%20Guide%2020201118%20Final.pdf](https://www.popdata.bc.ca/sites/default/files/documents/data/PCM/OSA%20LTC%20Survey%20(2016_17)%20Data%20User%20Guide%2020201118%20Final.pdf)



**National Care  
Experience  
Programme**

