National Care
Experience
Programme

International Review of National End of Life Surveys

March 2021

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 currently under development in order to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

Table of Contents

Introduction

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

Measuring person-centred care involves the collection of 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.[3] Evidence has shown that the three pillars of quality should be looked at as a group and not in isolation.[4]

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 several 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. 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.[5,6] 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 policy developers 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 care 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 people-centred health and social care service.[7] 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 [8] and the National Cancer Strategy 2016-2026.[9] Similarly, Sláintecare, the ten-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”. Sláintecare explicitly sets out the development and expansion of systems to capture patient experience.[10]

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.[11] 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.[12]

A commitment was subsequently made by HIQA, the HSE and the Department of Health to establish the National Care Experience Programme (NCEP), tasked with running the National Inpatient Experience Survey and expanding 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, in particular care at end of life.

National context of end of life surveys in Ireland

National reports, guidance, research and policy documents recognise the importance of the provision of good care at end of life and recommend evaluating the care delivered through surveying bereaved relatives.[13-17] In the absence of a standardised national end of life survey, surveys of bereaved relatives in Ireland to date have been undertaken by individual service providers on standalone basis or through a collaboration of the voluntary and state healthcare service providers.[17-19] Further detail on the policy context and background to surveying bereaved relatives in Ireland is outlined in Appendix 1 of this report.

Structure of this report

This documents sets out the findings of the international review undertaken to inform the development of a national end of Life survey for Ireland. It includes a summary of the findings and detail of surveys undertaken in each jurisdiction reviewed. The appendices include information on the context of health policy and background underlining the National Care Experiences Programme work on this survey along with information on the personnel consulted in each jurisdiction reviewed in this report. We would like to acknowledge the VOICES MaJam Team for their input into the development of the National End of Life Survey. This report is proudly supported by Irish Hospice Foundation.

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 end of life survey. To date, there is no standardised national approach in Ireland to capture the experience of care of those who have died, from the perspective of bereaved relatives.

There are significant differences between adults' and children's end-of-life care which are beyond the scope of this review, therefore surveys associated with the death of children are not included.

This report therefore identifies how organisations and agencies internationally collect and use bereaved relatives experience data associated with the death of an adult. Through identifying international best practice, this review is a step towards informing the National Care Experience Programme on the most advantageous approach to implement a national end of life survey in Ireland.

Methodology

A scoping review of international literature on bereaved relatives experience surveys was undertaken. This review found that surveying bereaved people is undertaken by many national public health agencies, healthcare providers and academic institutions internationally. Most surveys use data from bereaved relatives’ experiences of care for the purpose of evaluation of care at end of life.

Surveys from several countries were reviewed. Four countries were selected to be reported in detail for this review based on the criteria that the country conduct surveys of bereaved relatives that are:

- underpinned by legislation or health policy
- and/or undertake such surveys to evaluate the provision palliative care or care at end of life on a national basis.

The surveys reviewed in this report are in the following countries:

- United States of America
- England
- New Zealand
- Japan

Findings for this scoping review were compiled on each country, from literature including technical reports, national policy documentation and peer reviewed journal articles. Detailed discussions with key personnel with responsibility for management of bereaved relatives experience surveys within each country, where available also took place. Appendix 2 lists the personnel who were consulted within each organisation.

Each country selected is examined in relation to their governance, operational and reporting processes. The review of each country also focuses on the:

- context of death and dying, and policy underpinning the surveying of bereaved relatives
- survey governance structures, model, methodology, and administration
- sample population, distribution and collection methods, and response rates
- outputs including what is reported and what impact the results have had if reported or known
- the key themes and domains of care evaluated by each survey

Summary of Findings

A summary of the findings for surveys of bereaved relatives within a national context is set out below. The main themes are:

Objective

The overall objective of conducting a national end of life survey with bereaved people within each of the countries reviewed was to listen to the voices of the bereaved relatives as a way to evaluate the quality of palliative care and care at end of life provided to the person that died. Many countries also use the surveys to inform policy and improve the quality of care provided.

Governance arrangements

Governance arrangements vary between countries, however, all national surveys reviewed are underpinned by national health policy which endorsed the importance of surveying bereaved relatives to evaluate the experience of care at end of life. The national policy maker is involved in the governance arrangements of most programmes. Some countries such as the United States of America have adopted a partnership approach of governance, which includes the healthcare providers from the statutory, voluntary and private sectors working with the health policy maker. Other countries such as Japan and New Zealand also included academic professionals from universities who brought knowledge and expertise of palliative and end-of-life care.

Data protection

The legislative requirements around data protection are a significant consideration for care experience surveys in light of the large amount of personal data required to conduct these surveys. All of the jurisdictions examined considered carefully the collection and management of personal data within the parameters of legislation within each country. Data agreements and the sharing of data with a third party was managed by maintaining the anonymity of survey participants. This was done in many ways, such as through the assignment of a unique identification number.

Consent in each study was informed, voluntary and obtained from participants in compliance with data protection regulations. The rationale underpinning most surveys and the legislative context centred on the fact that the surveys were being conducted to evaluate the implementation of national health policy of the delivery of healthcare services for the purpose of improvement.

Ethical approval

Most surveys did not require ethical approval as they were underpinned by national health policy to evaluate care. In some countries such as New Zealand and Japan, ethical approval was sought as the surveys were conducted in partnership with universities. Bereaved relatives' experience surveys are a tool used in service evaluation and are thus regarded as an essential exercise in healthcare delivery and service improvement.

Communication

There were a number of methods deployed to increase response rates. Initial communication was no earlier than one month and no later than 24 months after bereavement in the countries reviewed. Increased responses rates were found when the first contact included the survey questionnaire and allowed the bereaved relative to opt-out.

The survey

Eligibility criteria

Careful consideration was given to the inclusion and exclusion criteria in each sample population. The inclusion criteria varied across countries from surveying bereaved relatives of people who died within a particular healthcare setting such as hospice or hospital or whilst under the care of a particular service such as palliative care. Others took a wider population based method and included all bereaved people of those who died within a particular time frame using death registration data to access the sample population.

Those excluded varied across the surveys reviewed, with two exclusion criteria common to all studies. Relatives of children who died and people who died suddenly or unexpectedly were excluded from all surveys. However, one study reviewed could not exclude the latter population due to the methods deployed.

The two common exclusion criteria across all surveys is largely based on two reasons. Firstly, there are significant differences between adults' and children's end-of-life care which are beyond the scope of this review and not addressed in the surveys reviewed which are focussed solely on the experience of adult deaths. Secondly, the bereaved relative's experience surveys reviewed were designed to capture data on the quality of care in the time leading up to a person's death and the interactions they had with health services. When a person dies suddenly and unexpectedly through for example homicide or death in an accident they were not necessarily in receipt of medical care. Therefore, bereaved family members would not be in a position to respond to questions asking about the provision of person-centred healthcare provided to the person that died given the unexpected nature of the death.

Survey respondent selection

Selection of the survey respondents and the terminology to describe respondent varies amongst the surveys reviewed, with surveys being administered to ‘family members or friends’, ‘bereaved family’, ‘ bereaved relatives’, ‘next of kin’, ‘caregiver’ or ‘informal caregiver’, ‘primary informal caregiver’ ‘informal carer’ of the ‘patient that died’, ‘deceased person’ or ‘decedent’. Bereaved relatives were primarily identified by two mechanisms in the countries surveyed for this review. The primary method of accessing information was by utilising the deceased persons’ healthcare record in the hospice or home hospice service provider, hospital or other healthcare facility and identifying the family member listed on this record.

Two studies utilised the country’s national death registration data from vital statistics to access a representative sample of the population who have died. In these studies, the International Classification of Disease (ICD) codes are used for sample population inclusion or exclusion purposes. Use of ICD codes allowed studies to exclude those who died suddenly and unexpectedly, thereby minimising the possibility of bereaved relatives from this population receiving a survey and potentially causing upset.

Most surveys suggest that the person who receives the questionnaire should pass it to the person who is best placed to complete the questionnaire. Some surveys also suggest that the questionnaire could be completed together with different family members.

Question pool and domains of care

An international library of validated questions is not available for bereaved relatives’ surveys as is the case for surveys of acute inpatient care. Most surveys have developed, tested and piloted their own questions or adopted some of those used in other surveys.

The content areas of the surveys reviewed broadly covered questions in the domains of care outlined in Table 1:

Domains of care	
Pain Management	Shared decision-making
Symptom Management	Dignity and Respect
Emotional / Psychosocial Care and Support	Preferred place of care and death
Spiritual Care and Support	Physical Environment
Personal Care	Support for relatives
Support with nutrition and fluid	Care in the last days of life and at time of death
Care provided by healthcare staff	Bereavement Support
Communication	Overall experience of care

Table 1 Domains of care and their content.

Most surveys reviewed include a number of demographic information questions relating to the person that died and those completing the survey, including questions on relationship to the person that died, age and educational attainment. The latter demographics are viewed as important as both factors are known to influence how bereaved people respond to surveys.

The majority of surveys also included a number of open–ended questions. Free texts comments provide bereaved people a ‘voice’ within surveys to outline aspects of care that they felt were delivered to a high standard and also offered them an opportunity to describe areas which required improvement.

Survey methodology

Mode of contact and timing

Most retrospective surveys contact respondents at least 3 months but less than 12 months after the death, taking care to avoid the Christmas period and the anniversary of the person’s death. Exceptions to this include the Bereaved Family Survey Family administered 1-3 months from death in the United States of America, to national surveys of bereaved relatives that utilise details from the death registration data and contact bereaved relatives up to 24 months after death in Japan. All of the surveys reviewed with the exception one in England use the postal system to contact survey participants. However, some surveys such as the CAHPS Hospice Surveys in the United States of America allow for different modes of administration including telephone interview.

Mode of response

The majority of surveys reviewed utilise a questionnaire and postal mode of response with a maximum of three mails out to non-responders.

One exception to this is the NACEL Quality Survey in England, where the method of response is online only. However, if the respondents in this survey have difficulty completing the survey online, they may contact a telephone based service who will provide assistance to the person.

A minority of surveys internationally also offered the opportunity for respondents to complete the survey over the telephone.

Response rate

The response rates of the surveys undertaken in the countries reviewed range from 18% to 67%. All surveys include the questionnaire in the initial contact made with respondents, with the exception of the Quality Survey undertaken by NHS Benchmarking in England. Respondents in this survey receive a letter with a unique URL code to allow completion of an online questionnaire.

Reminder letters and packs sent out to non-responders significantly increase the response rate. Other measures that increased response rate included a maximum of three mail outs and the inclusion of a questionnaire in subsequent survey packs to non-responders. One study in Japan found that the inclusion of a pen in the survey pack increased the response rate by 7.5% compared to those who didn’t a pen.

Frequency

The frequency of surveys vary considerably in the countries reviewed. In the case of the surveys reviewed from the United States of America, all relatives of people who have being cared for and died receiving support and care from hospice and palliative care services are surveyed.

Similar to surveys of acute inpatient care and maternity care, some countries conduct surveys on an annual basis whilst others do so every three-four years or alternatively, when funding becomes available.

Outputs

The survey results are analysed and reported in each of the countries examined. The results are published in a national report and depending on the purpose of the survey, are distilled into more detail at a local level.

National mortality follow back surveys such as the National Survey of Bereaved People (VOICES) in England and the National Mortality feedback survey in Japan report on national level data only.

Surveys focused on the quality of care delivered by healthcare services such as acute hospitals or hospices publish individual provider level reports along with national level results. The National Care at End of Life Quality Survey undertaken in England publish results at an individual hospital level on an interactive online site accessible to healthcare providers only. Surveys such as the CAHPS Hospice Survey in America publish data on an interactive online portal to facilitate the public viewing of results.

Impact

Health policy underpins the engagement of bereaved relatives to ascertain the quality of care at end of life in the countries reviewed. Policy also suggests that feedback from such surveys be incorporated into local and national quality improvement plans.

The impact of international end-of-life care experience surveys is reported favourably. The impact generally focuses on how results are used to measure the quality of care at end of life at a national level, and also at an individual healthcare provider level. Where individual reporting is available, the impact tends to focus on the use of survey findings for the purposes of quality improvement.

Surveys such as the National Survey of Bereaved People (VOICES) have been formally evaluated for its impact. This survey was described as a valuable source of data and useful as a national indicator of end-of-life care. This evaluation also suggested that an increased sample size with more local level VOICES findings would enhance the ability of healthcare service providers to use findings for service improvement.[20]

Survey findings have also been used to assess the implementation of national health policy and national clinical guidance by healthcare staff and providers.

The impact of the survey results have not been confined to healthcare as academic institutions report using survey results to enhance knowledge in the provision of palliative and end-of-life care and findings informed the delivery of education and training programmes.

The benefits of bereaved relatives' surveys are regarded as significant for all those involved, including:

- bereaved people
- service providers
- the regulator
- the policy developer
- future recipients of health and social care services.

Methodologies for National End of Life Surveys

United States of America

In 2018, there were 2.8 million deaths out a total population of 328 million people. People aged 65 and over account for 75 percent of all deaths in 2018 in the United States of America.[21,22]

The following is a review of the development and administration of two surveys which are used to capture relatives' perceptions about the quality of care at end of life in the United States with measures endorsed by the National Quality Forum.

The surveys reviewed for the United States in this report are the:

1. Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice survey.
2. Bereaved Family Survey (BFS) developed and administered by the United States Department of Veterans Affairs.

The information was obtained from a review of the literature including technical reports, peer-reviewed journal articles and follow-up communication with the United States, Centers for Medicare & Medicaid Services (CMS).

CAHPS Hospice Survey

Background

The CAHPS Hospice survey is part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care provided by hospice care teams in all settings.

The Centers for Medicare & Medicaid Services which is part of HHS, conducts this survey to improve hospice care, as the Centers for Medicare & Medicaid Services (CMS) pays for most of the hospice care in the U.S. CMS is responsible for ensuring that hospice patients and their families receive high quality care.[23]

Hospice care in the United States is provided in the three main settings of home, nursing home and inpatient, the latter includes freestanding hospice inpatient units and acute care hospitals.

The survey was designed to measure and assess the experiences of people who died while receiving hospice care from the perspective of their primary informal caregiver, whether a family member or friend.

CMS partnered with the RAND Corporation to design and field-test the CAHPS Hospice Survey in 2012.[25] The CAHPS Hospice Survey was developed with the input of stakeholders such as government agencies, consumer groups and palliative care organisations involved in the provision of hospice care.[26] In November 2014, the federal Office of Management and Budget (OMB) gave approval for the national implementation of the CAHPS Hospice Survey instrument. It was reviewed and approved again by OMB in 2017.

The National Quality Forum (NQF) is a voluntary consensus and standard-setting organisation established to standardise healthcare quality measurement and reporting in the United States that is underpinned by legislation. Following extensive consultation, the Board of NQF endorsed the six composite measures and two single-item global measures from the 47-item CAHPS Hospice Survey instrument for the purpose of measuring performance, accountability and quality improvement in palliative care and end-of-life care services.[27,28]

Objective

The survey aims to produce comparable data on the deceased persons' and caregivers' perspectives of care that allow independent, objective and meaningful comparisons across hospice care providers on domains that are important to those receiving the care and create incentives for hospices to improve their quality of care.[24]

The survey was developed to:

1. provide a source of information from which selected measures could be publicly reported to beneficiaries and their family members as a decision aid for selection of a hospice program
2. aid hospices with their internal quality improvement efforts and external benchmarking with other facilities
3. provide CMS with information for monitoring the care provided.

The CAHPS Hospice survey considers the deceased person (i.e., the patient who died while in hospice care) and his or her caregiver (i.e., family member or friend) as the unit of care.

Governance arrangements

The Affordable Care Act 2010, Section 3004 directs the CMS to establish quality reporting requirements for hospice programs titled the Hospice Quality Reporting Program. The Hospice Quality Reporting Program includes data submitted by hospices through the Hospice Item Set (HIS) data collection tool, and the CAHPS Hospice experience of care survey.[24]

The Agency for Healthcare Research and Quality (AHRQ)'s mission is to produce evidence that makes healthcare safer, higher quality, more accessible, equitable, and affordable. AHRQ develops the knowledge, tools, and data needed to improve the healthcare system and help the American people, policymakers and healthcare professionals make informed health decisions.

The Centers for Medicare & Medicaid Services (CMS), a federal agency within the Department of Health and Human Services (HHS) developed the hospice survey to systematically assess patient and caregiver experiences with hospice care and received approval of the survey by AHRQ.

The survey is part of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) family of surveys and is officially designated by CMS as the CAHPS® Hospice survey. CAHPS® is a registered trademark of the Agency for Healthcare Research and Quality.

The survey

The sample

The CAHPS Hospice Survey is designed to be completed by the person who is most knowledgeable about the hospice care given to the deceased person, referred to here as the primary informal caregiver. The caregivers are eligible for inclusion in the sample frame if they meet the following criteria:

- the deceased person was aged 18 and over at time of death
- the deceased person died at least 48 hours following last admission to hospice care
- there is a caregiver of record
- the caregiver is someone other than a non-familial legal guardian
- the caregiver has a U.S. or U.S. Territory home address

Caregivers are excluded from the sample if they inform hospice staff during their relative’s care that they do not wish to be contacted. This is classified as a “No publicity” status request and is seen as a rare and unusual request.[28]

Distribution and collection

The survey is administered by CMS approved vendors on behalf of hospices. Hospices are required to contract with an approved survey vendor and to provide bereaved relatives contact information to the vendor on a monthly basis.

The survey may be administered by post only, telephone only or a mixed mode of post and telephone. The mixed mode survey administration includes one survey by post with telephone follow-up. No other modes of survey administration are permitted.

Data collection is initiated two months following the month of the person’s death e.g. if a person dies on 22 January, the first questionnaire and cover letter will be mailed on 1 April. A second questionnaire with a follow-up cover letter is sent to all sampled caregivers who did not respond to the first questionnaire, approximately 21 calendar days after the first questionnaire mailing. The time of the field period, from initial contact is never longer than six weeks.

Hospices with fewer than 50 survey eligible caregivers during the prior calendar year can apply for exemption from the survey data collection and reporting requirements. This usually because the hospice has recently opened and the limited size of the sample population for reporting.

CMS conducted a mode experiment in 2015 to ascertain if the mode of survey administration in which caregivers respond to the survey systematically affects CAHPS Hospice Survey results. CMS introduced a mode adjustment framework to the scores to ensure that the CAHPS Hospice Survey scores reflect differences in quality and not any differences that are the result of the mode of survey administration such as by mail or telephone.[24]

Case mix adjustment and weighting has also been deployed when reporting CAHPS Hospice Survey results. Adjustments take account of the respondent’s age, education, relationship with the deceased person, survey language and language spoken at home and response time from time of death to completion of survey. Case mix adjustors considered for the person that died include, the person’s age, primary diagnosis and length of final admission. Case-mix adjustment is utilised to ensure that characteristics that may influence survey responses and therefore results which are beyond the control of the hospice care providers are taking account of.

Communication

The first point of contact for bereaved relatives with the CAHPS Hospice Survey is receipt of the survey pack which includes, an invitation letter, the questionnaire and postage paid return envelope. Participation is encouraged by addressing questions on the purpose of the survey and concerns about participation. Instructions on how to respond are also included along with information on where results are published.

Response Rate

The CAHPS Hospice Survey reporting of results reveal the large scale nature of this survey with 2,795 hospices reporting their CAHPS Hospice Survey scores based on 622,320 completed surveys as outlined in Table 2:

Reporting on hospice care experiences for people who died in:	(4/1/2015 to 31/1/2017).	(10/1/2016 to 30/9/2018).	(10/1/2017 to 30/9/2019
Number of Hospices reporting on CAHPS survey scores:	2,795	2,907	2,938
No. of CAHPS Hospice Surveys completed :	622,320	656,620	657,548

Table 2: Response rate of the CAHPS Hospice Survey 2015-2019

Just over 2 million people were surveyed as part of the CAHPS Hospice Survey from April 2017 to March 2019 with a 32.3% response rate.

Table 3 outlines details of response rate by the three different modes of administration for this time period: [29]

Q2 2017-Q1 2019	Mail Only	Telephone Only	Mixed	Overall
Surveyed (Eligible)	1,931,571	41,440	46,885	2,019,896
Completed Survey	623,404	9,908	18,733	652,045
Response Rate	32.3%	23.9%	40%	32.3%

Table 3: Response rate of the CAHPS Hospice Survey by mode of administration

Customer Support Lines

Survey vendors who administer the CAHPS Hospice Survey must maintain a toll-free customer support telephone line to answer questions about the CAHPS Hospice Survey, offering customer support in all languages in which the survey vendor administers the survey. Survey vendors conducting the mail only or mixed modes of survey administration must include contact information for their customer support telephone line in the initial and follow-up cover letters. Survey vendors must document questions received and responses provided via a database or tracking log.

A CAHPS Hospice Survey Frequently Asked Questions (FAQ) document for customer support personnel and project staff is provided. Customer support personnel must use the FAQ as a guide when answering caregivers' questions about the survey.[24]

More details about the survey and administration guidelines can be found at the survey website: www.hospicecahpssurvey.org.

Outputs

Since 2015, all Medicare certified hospices who meet the eligibility criteria are required to administer the survey on a monthly basis in order to receive the full Annual Payment Update from CMS.[23] Submission of data is seen as compliant for the purposes of full Annual Payment. Exemptions are provided for very small hospices and those who are new in recognition of the limited size of the sample population for reporting.

Official CAHPS Hospice Survey scores are publicly reported four times each year on the Medicare Care Compare website: www.medicare.gov/care-compare/

Due to reporting exemptions granted because of the COVID-19 pandemic, the publicly reported data was frozen with the November 2020 update and will remain frozen until the February 2022 update.[29]

The questionnaire

The survey questionnaire is available in English, Spanish, Chinese (Mandarin and Cantonese), Russian, Portuguese, Vietnamese, Polish, and Korean.

The CAHPS Hospice Survey instrument consists of 47 questions, broken into three sections: Core questions (Q1 – Q40), About Your Family Member (three questions) and About You (four questions).[30,31]

The eight CAHPS Hospice Survey quality measures consist of six composite (multi-item) measures and two single-item global measures. Questions are combined into similar themes.[32] The Composite measures are:

1. communication with family
2. getting timely help

3. treating the patient with respect
4. emotional and spiritual support
5. help for pain and symptoms
6. training family to care for patient.

The Global Measures in the CAHPS Hospice Survey are:

Rating of Hospice

- Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member’s hospice care?

Willingness to Recommend this Hospice

- Would you recommend this hospice to your friends and family?

The Bereaved Family Survey

Background

The United States Department of Veterans Affairs (VA) was created to care for military veterans and is made up of a number of distinct services, including the Veterans Health Administration (VHA). The VHA is described as America's largest integrated healthcare system.[33,34] The VHA has a budget of $80 billion per annum and provides care at 1,255 healthcare facilities, including 179 inpatient sites serving 9 million veterans each year.[33,35,36]

Objective

The Bereaved Family Survey (BFS) is part of a national initiative developed by the United States Department of Veterans Affairs (VA) to evaluate the quality of care and outcomes in all VA inpatient settings across the United States including Puerto Rico.

The BFS is administered to family members of people who have died in the inpatient settings such as nursing home, freestanding hospice inpatient units and acute care hospitals. The Bereaved Family Survey is used to measure family satisfaction based on the care received in inpatient Veterans Affairs Medical Centers nationwide and more recently in homes.[37]

The BFS is managed internally by the Department of Veterans Affairs (VA), Veteran Experience Center's whose objectives are:

- To identify and reduce unwanted variation in the quality of end-of-life care throughout the VA
- To define and disseminate processes of care ("Best Practices") that contribute to improved outcomes for Veterans near the end of life and their families.[35]

Governance arrangements

The Department of Veterans Affairs (VA), Veteran Experience Center, based in Philadelphia is charged with collecting quality data to evaluate and guide the VA's Hospice and Palliative Care Program. The Department of Veterans Affairs (VA) has used the Bereaved Family Survey to evaluate end-of-life care in all its inpatient services since 2008. The BFS was adapted from the validated Family Assessment of Treatment at End of Life Short Form (FATE-S).[34] The Bereaved Family Survey was a pilot Performance Measure for the Office of Quality and Performance, Department of Veteran Affairs, beginning in 2010. The National Quality Forum (NQF) is a voluntary consensus and standard-setting organisation established to standardise healthcare quality measurement and reporting in the United States that is underpinned by legislation. One global rating question in the BFS is a nationally endorsed performance measure by the National Quality Forum. The Bereaved Family Survey has been approved for use by the federal Office of Management and Budget.

The survey

The sample

Veterans who die in one of the inpatient Veterans Affairs Medical Centers (VAMCs) nationally are included in the sample, excluding:

- deaths within 24 hours of admission (unless the veteran had a previous hospitalisation of at least 24 hours in the last month of life).
- veterans for whom a next of kin (NOK) is not knowledgeable about the care received during the last month of life
- veterans for whom a NOK is not listed in the medical record
- veterans for whom a NOK has incomplete or incorrect contact information.

Family members may be excluded from participation in the BFS for any of the following reasons:

- they decline to participate in the survey or do not agree to be interviewed
- they feel too uncomfortable to answer the survey questions, or they are reluctant to discuss details about the Veteran's death
- they do not feel informed enough to answer questions about the Veteran's last month of life
- they do not speak English or Spanish.[35]

The survey is mailed along with a letter from the director of the Veteran Experience Center to family members, four to six weeks after the veteran's death.

- Family members are asked to return the paper copy of the survey, complete the survey online, or call the Veteran Experience Center to complete the BFS over the phone with a research coordinator.
- If a completed survey is not returned by mail, a reminder postcard with contact information (for completing the survey over the phone, or to receive

another mailed copy of the survey) and instructions for completing the survey online is sent.

- A second copy of the Bereaved Family Survey is sent by mail, if there is no response from the previous contact.
- Family members who have not responded to the survey after all three mail contacts receive a reminder follow-up phone call.[35]

The BFS is published in four formats (English with female and male pronouns, Spanish with female and male pronouns) in order to accommodate diversity in the population.

For example:

> In [NAME's] last month of life, how much of the time did the staff who took care of [HIM/HER] provide you and [NAME] the kind of emotional support that you and [HE/SHE] would have liked prior to [HIS/HER] death?
>
> Would you say: Always, Usually, Sometimes, Never, Did not want/need emotional support

A web based version was introduced in 2014 and 7% of surveys are completed by this method.[34]

Response Rate

The BFS had a 60% response rate in 2011 with 11,888 bereaved relatives responding.[36] Thorpe (2016)[34] found that 82,233 people died in the period October 2009 – September 2013 in one of the 146 inpatient VA medical centers, with 43,327 people completing the BFS during this time a 56% response rate. Gray (2020)[37] notes that nearly 6,000 bereaved relatives responded to the BFS in 2017.

Outputs

The Veteran Experience Team have adopted analytic and reporting practices that are used by other federal and private quality improvement and accountability organisations.[38]

The Bereaved Family Survey results are collected and analysed by the Veteran Experience Center team and scores are reported on a four-quarter cumulative scores basis. This is to address the concern of small sample sizes of less than 30 responses which is not large enough to provide stable estimates. To address this issue, scores are reported from the most recent quarter plus the previous 3 quarters.

The Bereaved Family Survey aggregated results are reported to each VA medical facility, VA stakeholders, which include VA leadership, policy experts, clinicians, and researchers on a quarterly basis.[35]

Impact

The findings provide valuable insights into opportunities for improvement for the various stakeholders including the individual VA medical facilities, VA leadership, policy experts, and health and social care professionals.[35]

The questionnaire

The Bereaved Family Survey consists of 19 questions in total, 17 structured and closed-ended items that require respondents to rate the care the veteran received in the last month of life and two open-ended items that ask respondents to provide any additional comments for improving EOL care.

The closed questions ask relatives to assess:

- interactions with staff
- communication with family members about the patient's condition and timing of death
- management of the patient's hygiene and pain
- provision of emotional support before and after death and anxiety at EOL
- spiritual support
- information provided on burial and funeral benefits, benefits for surviving spouses and dependents
- overall rating of care in final month of life.

The two open-ended questions ask relatives to make comments about the care provided:

- Is there anything else that you would like to share about [PATIENT'S] care during the last month of life?

  Is there anything else that you would like to share about how the care could have been improved for [NAME]?

The BFS Performance Measure (BFS-PM) consists of a single item on the BFS that asks respondents to provide a global rating of care during the last month of life.

- Overall, how would you rate the care that [NAME] received in the last month of [HIS/HER] life? Would you say: Excellent, Very good, Good, Fair, Poor

The BFS-PM is divided into ‘Excellent’ versus all other responses (i.e., ‘Very good, Good, Fair, Poor’) and the facility/organisational-level BFS-PM score reflects the percentage of respondents that rate care as ‘Excellent’. The BFS-PM is endorsed by the National Quality Forum.

Key Lessons Learned and Recommendations from the United States of America

- All Hospice providers in the United States that meet the eligibility criteria are obliged to survey bereaved relatives and provide the data to the CMS to ensure they receive full Annual Payment Update.
- The CAHPS Hospice Survey and the Bereaved Family Survey address similar domains of care at end of life; including the overall quality of care, communication, pain and symptom management, emotional and spiritual support and both have measures endorsed by the National Quality Forum.
- Both surveys are designed to be administered to the person who is most knowledgeable about the care received by the person who died and exclude relatives of people who died within either 24 hours (Bereaved Family Survey) or 48 hours (CAHPS Hospice Survey) of admission to the facility.
- Administration of both surveys and timing is different, in the case of the CAHPS Hospice Survey, bereaved relatives are contacted at a minimum of 2 months from the person’s death, whereas the BFS survey is usually administered one month to six weeks following the person’s death.
- Management and administration of the survey can be completed internally within an organisation, as in the case with the BFS or using external vendors who follow a detailed code of administration and practice in the case of CAHPS Survey. Both surveys can be completed by mail or if preferred, on the telephone. The BFS survey may also be completed online.
- The CAHPS Hospice Survey have detailed methods in place to address queries or concerns of bereaved relatives as each service administering the survey has a dedicated customer support telephone line.
- The CAHPS Hospice survey team recommend reporting results which take account case-mix adjustment measures including age, education, language

and ethnicity of the respondent, and age, length of stay and primary diagnosis of the deceased person to take account of difference that are beyond the control of care providers.

- Surveys of bereaved relatives are a recommended method of measuring and reporting on the quality of care provided by hospice care providers in all healthcare settings for the purposes of accountability to the Centers for Medicare & Medicaid Services who fund the majority of hospice care in the United States.

England

In 2019, there were 496,370 deaths registered in England out of a total population of 66.8 million people.[39]

Surveying bereaved relatives to enhance end-of-life care has been utilised by the National Health Service (NHS) England, individual hospitals, hospices and other healthcare providers in England for many years.[40]

The following is a review of surveys which have been recommended by national health policy and are used by the NHS in England to investigate the quality of care in the time leading up to the person's death from the perspective of bereaved relatives.

The national end of life experience surveys reviewed for England in this report are the:

- National Survey of Bereaved People (VOICES – Views of Informal Carers Evaluation of Services), 2011 to 2015
- National Care of the Dying Audit for Hospitals (NCDAH) England 2013-2016 and National Audit of Care at the End of Life (NACEL), 2017 to date

Surveying bereaved relatives is undertaken by many healthcare providers in England at a local hospital and hospice level. Many hospices survey bereaved relatives through their participation in the FAMCARE survey carried out annually by the Association for Palliative Medicine of Great Britain and Ireland.[41]

Surveys such as this and others conducted by partnerships between healthcare facilities and academic institutions highlight the widespread use of bereaved relatives experiences of care for the purpose of continuous evaluation and improvement of care at end of life. These surveys are beyond the scope of this review, as they are carried out independently by the organisations involved and not on behalf of NHS England.

The information below was obtained from a review of the literature, including technical reports from the Office for National Statistics (ONS), National Care of the Dying Audit for Hospitals, the National Audit of Care at the End of Life peer reviewed journal articles and follow-up communication with NACEL.

National Survey of Bereaved People (VOICES)

Background

The National Survey of Bereaved People (VOICES) was conducted by the Office for National Statistics on behalf of NHS England for the first time in 2011, and repeated annually until 2015 with the last report published in 2016. NHS England ran a public consultation in 2015 on the National Survey of Bereaved People (VOICES), a summary of its findings are reported on later in this review.

The VOICES survey instrument was based upon the 1991 regional study of the care of the dying, which in turn was based upon Cartwright's study of the 1969 and 1987.[42] The National Survey of Bereaved People (VOICES) questionnaire was developed by Professor Julia Addington-Hall and colleagues from the University of Southampton, following extensive research asking bereaved relatives about their perceptions of the care given to their deceased relative or friend.[43]

Following publication of the Department of Health's End of Life Care Strategy in 2008, Professor Addington-Hall was commissioned by Department of Health to modify the standard VOICES questionnaire to measure all the key elements relating to the quality of end-of-life care identified in the strategy. This resulted in the development of the VOICES questionnaire, known as the National Survey of Bereaved People (VOICES). VOICES is an acronym for Views Of Informal Carers Evaluations of Services. The new survey tool was extensively tested, demonstrating its feasibility and acceptability in measuring the key elements relating to the delivery of quality end-of-life care as set out in Strategy. Results showed that the questionnaire could detect differences in the quality of care provided in different settings for example, hospitals versus hospices.[42]

The review of the Liverpool Care Pathway (Neuberger 2013) raised issues with aspects of end-of-life care, which were not measured by the VOICES survey. As a result, new questions were developed and the whole survey was reviewed and cognitive tested with bereaved people. The resulting changes were implemented in the National Survey of Bereaved People questionnaire in 2014.

Objective

The objective of the National Survey of Bereaved People (VOICES) survey is to look at the quality of care in the last 3 months of life in each different setting such as home, acute hospital, hospice or nursing home. It therefore provided nationally representative data on the experiences of people who have died in England regardless of the setting or cause of death. The reports published by the ONS were made publicly available to inform palliative and end-of-life care practice, policy and the provision of care services including for example within different care settings, age groups and causes of death.[42,43]

Governance arrangements

The National Survey of Bereaved People (VOICES) was commissioned by the Department of Health in 2011 and 2012, and subsequently by NHS England from 2013 following the restructuring of the Health and Care systems in England in April 2013. The survey was administered by the Office for National Statistics (ONS).

The survey

The Sample

Each year a sample of approximately 49,000 adults in England was selected from the deaths registration database held by Office for National Statistics (ONS).

Since 2012, deaths were selected from those which occurred between January and April. To limit any seasonal change in the annual death register used for the VOICES survey sample, the time frame for sampling remained constant as ONS research found that a greater number of deaths were registered in winter and more older people died at this time.

The ONS record and code all details relevant to the cause of death on the death certificate using the International Classification of Diseases, Tenth Revision (ICD–10).

Exclusions

Deaths were excluded from the sampling frame where the underlying cause of death was accident, suicide or homicide (ICD–10 codes V01 to Y98 and U50.9). Other deaths that were excluded include:

- deaths of people aged under 18 years
- or where the death had occurred “elsewhere” than the designated locations (home, care home, hospital or hospice)
- or where address details of the informant were missing.

Inclusions

The following deaths were included where they were recorded as the underlying cause:

- cardiovascular disease, (CVD), 29% of the selected sample
- cancer, this includes benign neoplasms, 30% of the selected sample
- other, excluding CVD and Cancer, 41% of the selected sample [43]

To ensure a representative sample of deaths in England, the sample was stratified by cause of death, place of death and geographic spread.[43]

The sample for the 2014 VOICES survey was selected from the adult deaths registered between 1 January 2014 and 30 April 2014, which were extracted from the ONS death registration database. From the 135,880 deaths that were eligible for the survey, a stratified sample of 49,614 was drawn for the actual survey. In 2014 - 21,403 people responded.[44]

The sample for the 2015 VOICES was taken from the 155,257 deaths that were eligible for the survey, a stratified sample of 49,558 was drawn for the actual survey.

Distribution and data collection

The VOICES questionnaire is sent by post by the ONS to the person who registered the death of the person that died; usually a relative or friend. A letter of introduction suggests that if this person feels unable to take part, or if they deem it appropriate, they should give the questionnaire to another family member or friend of the deceased person for completion.

Relatives are contacted between 4 and 11 months following the death with the data collection period running for approximately 15 weeks. The mailing period is also timed to exclude Christmas and the anniversary of the person's death.

The survey has a maximum of three mail-outs to prospective respondents. The first comprises a mail-merged, personalised questionnaire, a pre-paid return envelope and an information leaflet. A reminder letter is sent 3 weeks after the first mail-out to non-responders only, followed by a final invitation to take part a month later, if no response has been returned. The ONS VOICES Survey pack includes a postage paid envelope that permits return of questionnaire from bereaved relatives living abroad.

Each pack also contains an information leaflet with frequently asked questions with details of the postal address of the ONS office in Wales and the ONS Survey Enquiry Line. Calls of a particularly sensitive nature or expressing a serious complaint are directed to the survey manager who deals with them directly. Contact details were provided for the national charity providing bereavement support, Cruse Bereavement Care. Cruse provided telephone advice and support for respondents who required it.[46,47]

Communication

The first point of contact for bereaved relatives with the VOICES Survey is receipt of the survey pack which includes, an invitation letter, the questionnaire and participant information leaflet. The leaflet provides information about the survey with a frequently asked questions (FAQ) which addresses questions on the purpose of the survey and concerns about participation. Instructions on how to respond are also included, along with information on opting out. An ‘opt out’ box was added to the back of the questionnaire that respondents could tick if they did not wish to take part in the VOICES 2012 version and thereafter. Information on where results are published are also included in the survey pack.

Response rate

Over a five year period, 246,752 people received the VOICES Survey with 110,311 people responding to the survey and average of 45% response rate.

The overall response rate was on average 46% for the years 2011-2013 and 43% for the 2014 and 2015 survey as outlined in Table 4:

	2011	**2012**	**2013**	**2014**	**2015**
Number included in sample	48,766	49,207	49,607	49,614	49,558
Number of respondents	22,292	22,635	22,661	21,403	21,320
Response Rate	45.7%	46%	46%	43%	43%

Table 4: Response rate of the National Survey of Bereaved People (VOICES) 2011-2015

Outputs and impact

The ONS published a comprehensive results report for each year of the survey online. The data is published by the ONS on their website 15-21 months after the care to which it relates was received. The National Survey of Bereaved People (VOICES) was evaluated by NHS England and is described as a valuable source of data and useful as a national indicator of end-of-life care. The evaluation also found that an increased sample size with more local level VOICES findings would enhance the ability of healthcare service providers to use findings for service improvement.[20]

The National Survey of Bereaved People (VOICES) has provided significant insights into the quality of care delivered to people in the last three months of their lives. The

National Health Service and the Department for Health in England utilise the information to inform policy decisions and evaluate the quality of end-of-life care. According to the ONS, other users of the statistics include a range of organisations and people involved in end-of-life care, including the National End of Life Care Network, the National End of Life Care Programme, academics, health researchers and charities.[43] The National Institute of Health and Care Excellence have also used data to assess the implementation and compliance to its guidance.[48]

Current status of the National Survey of Bereaved People (VOICES)

NHS England ran a public consultation in 2015 on the National Survey of Bereaved People (VOICES) and published a report summarising the feedback from the consultation.[20] Key findings of this report include:

- VOICES survey was valuable source of data and useful as a national indicator of end-of-life care.
- Healthcare providers noted the importance of having national data and found the survey findings most valuable when used for local service improvement.
- The majority of respondents identified the time lapse between the point of care and the publication of results (15-21 months) as a limiting factor in the utility of the VOICES survey for service improvement.
- The majority of respondents indicated that an increased sample with more local level of VOICES findings would enhance their ability to use findings for service improvement.
- A number of healthcare providers reported commissioning local surveys such as the Care of the Dying Evaluation (CODE) survey to supplement the data provided at a national level by VOICES for the purposes of ascertaining the quality of care at a local level.

In light of the consultation findings, NHS England is working with the Office of National Statistics to address issues raised in the consultation report. A recent parliamentary question noted that ‘safeguarding arrangements on data-sharing, designed to ensure any concerns about care raised via the survey can be appropriately investigated, have resulted in delays to commencing the new VOICES survey’. The response also stated ‘NHS England is exploring the piloting of experience measures, including use of the VOICES survey, at a local level, in a number of National Health Service end of life care demonstrator sites’. [49]

The National Institute of Health and Care Excellence published a progress report on the impact made by the health and care system in implementing NICE guidance on end-of-life care in 2020. This report draws heavily on the evidence from the experiences of care reported by bereaved relatives in the National Survey of Bereaved People (VOICES) and also draws on evidence from the data in the National Care of the Dying Audit for Hospitals England and the National Audit of Care at the End of Life reports. [21]

National Care of the Dying Audit for Hospitals (NCDAH) England 2013-2016 and National Audit of Care at the End of Life (NACEL), 2017 to date

Background

The Healthcare Quality Improvement Partnership (HQIP) commission, manage and develop the national clinical audit and patient outcome programme on behalf of the NHS in England since it was established in 2008.

HQIP commissioned the National Care of the Dying Audit for Hospitals England which was organised by the Royal College of Physicians up until 2016. Following a tender by HQIP in 2017, the contract was awarded to the NHS Benchmarking Network for three audit cycles over three years focusing on the quality and outcomes of care experienced by those in their last admission in NHS funded acute, community and mental health hospitals throughout England. [50] The audit was subsequently titled the National Audit of Care at the End of Life (NACEL).

The surveys conducted as part of the National Care of the Dying Audit for Hospitals England and the National Audit of Care at the End of Life were utilised to capture the experience of care at a local healthcare provider level, as part of a wider audit structure commissioned by HQIP on behalf of NHS England.

The National Care of the Dying Audit for Hospitals (NCDAH) 2013/14 departed from previous audits with the inclusion of an optional survey of bereaved relatives. The three elements to the National Audit include:

- An organisational audit which focusses elements that underpin the delivery of care at end of life at an organisational level.
- A case note review which was anonymised and completed on a consecutive basis of all patients who died (excluding sudden unexpected deaths) within participating hospitals.
- An optional survey capturing the views of bereaved relatives was introduced in 2014. The Care of the Dying Evaluation (CODE) survey tool was utilised to

assess care delivery in the last days of life from the perspective of bereaved relatives within hospitals.

All Audits from 2014 audit had a survey of bereaved relative's component with the exception of the End of Life Care Audit: Dying in Hospital (2016) which centred on an organisational audit and case note review. However, the Audit of 2016 asked hospitals if they had surveyed bereaved relatives and made service improvements associated with this feedback, instead of providing a survey of bereaved relative's component. Eighty percent of trusts reported seeking bereaved relatives views using a variety of mechanisms and sixty-seven percent of trusts reported that they implemented change to their service as a result of their assessment of bereaved relatives' perspectives.[51]

Objective

The audit objectives for NCDAH and for the NACEL from 2017 onwards are to:

- assess compliance with national guidance on care at the end of life
- measure the experience of care at the end of life for dying people and those important to them
- provide audit reports and outputs thereby enabling stakeholders to identify areas for service improvement
- provide an overview of progress with the provision of high-quality care at the end of life.[52]

Governance arrangements

The Healthcare Quality Improvement Partnership (HQIP) commissions these audits on behalf of NHS England. The Royal College of Physicians administered the National care of the dying audit for hospitals (NCDAH) England up until 2017. The NHS Benchmarking Network have undertaken the audit since 2017 and the titled changed to the National Audit of Care at the End of Life (NACEL).

Ethical approval and data protection

Ethical and data protection measures are central to the Healthcare Quality Improvement Partnership (HQIP) audits commissioned on behalf of NHS England. The National Audits and their constituent parts including the bereaved relatives' surveys meet the requirements of General Data Protection Regulation (GDPR). Specifically NHS Trusts and Health Boards use regulations set out in GDPR as the legal basis to undertake clinical audit in direct care, under the provision Article

6(1)(e) of GDPR, '...for the performance of a task carried out in the public interest or in the exercise of official authority..', and also use GDPR Article 9(2)(h) condition where data 'processing is necessary for the purposes of ..., the provision of health or social care or treatment or the management of health or social care systems and services'. [53]

The National Audit of Care at the End of Life has Data Protection Impact Assessment in place addressing the legal basis for the data collection as outlined above, and mitigating action for potential data breaches. NHS Benchmarking provide detailed support on information governance to all healthcare facilities participating and also suggest that all participants follow their own internal information governance processes. Organisations are directed to consider their organisation's Fair Processing Notices which should cover internal processes for contacting carers for surveys of this type. A Cause for Concern Policy outlines the process for when a carer outlines a potential cause for concern and its management thereafter.

The survey

The sample

The bereaved relatives surveys conducted as part of the National Audits were designed to be administered to the person identified on the healthcare record as the 'next of kin' or family member listed as the contact person. The bereaved relatives of the person who died are eligible for inclusion in the sample frame if the death occurs within the time frame of the Audit. For example, Audit participants were requested to send an invitation to participate in the Quality Survey to the bereaved relatives of those who died in April and May 2019.[54]

Method of distribution, collection and response rates

The National Audits conducted to date adopted similar methods of distribution, and collection of data as participating hospitals sent the survey to the bereaved relative or friend who was identified as the patient's next of kin or contact named on the healthcare record. However, each National Audit had different levels of participation from hospitals, with different survey tools and different response rates. An outline summary is provided noting variation between the different National Audits, including information on healthcare providers' participation, questionnaires used, methods deployed and response rates.

NCDAH Report 2014

Thirty-six trusts, equating to 27% of those participating in the audit undertook the survey of bereaved relatives using the CODE survey questionnaire. Bereaved relatives could complete the questionnaires online or return the hard copy directly to the site for subsequent data entry and reporting purposes. 858 surveys were returned out of a total of 2,313, a response rate of 37%.[55]

End of Life Care Audit report 2016

This Audit did not provide a survey of bereaved relative's element. However, hospitals were asked if they sought feedback from the bereaved. The report noted that 80% of trusts (114 of the 142 trusts) sought bereaved relatives' and friends' views between April 2013 and March 2015. Ninety-four percent utilised a questionnaire, with 45% (48/107) using a locally developed survey, 27% (29/107) utilising the CODE survey or a modified version and 23% (25/107) using the VOICES Survey. One of the recommendations of this report stated that 'all trusts should seek bereaved relatives' views, and results should be fed back to the trust's board as well as the public'.[51] Interesting, 67% reported (76/114) that they had implemented changes to their service as a result of undertaking a survey of bereaved relatives.

NACEL of 2018-19

One hundred and fourteen organisations in England participated in the bereaved relative's survey known in this report as the Quality Survey element of the audit. Hospitals participating were requested to send the Quality Survey invitations to the bereaved relatives for all deaths occurring in April and May 2019. The letter contained a unique URL code which linked the response from the bereaved carer back to the hospital. The Quality Survey is completed online by the bereaved person. For those not able to complete the questionnaire online, the Patients Association ran a helpline and completed the survey online in discussion with the bereaved relative. The Patients Association have access to bereavement support information and direct bereaved relatives to bereavement organisations where appropriate. A total of 790 Quality Surveys were returned across England (759) and Wales (31), a response rate of 18% survey. A number of reasons were cited for the low numbers as trusts and hospital chose not to participate in this part of the audit for the following reasons:

- 'already undertaking a local bereaved persons survey
- contact details for relevant person not recorded or not easily accessible
- concerns regarding information governance processes as policies were not in place regarding the contacting of carers at the hospital or trust'. [56]

NACEL of 2019-20

One hundred and thirty organisations in England received at least one response from the Quality Survey element of the Audit. The Quality Survey questionnaire is sent to the 'nominated person(s)' of all patients who died within the audit timeframe in acute and community hospitals. Fifty-eight percent of organisations eligible participated in the Quality Survey element of the Audit. Reasons for not participating in the survey mirrored those from the previous report. Of the 1,581 people that completed the bereaved relatives Quality Survey, 1,516 were from bereaved people in England. The response rate was 18%, which was the same as for the previous report although almost twice as many Quality Surveys were returned. The increase was due to changes in the way the Quality Survey was administered as it was no longer linked with the case note review element of the Audit as was done so in the previous round. For budgetary reasons, and to limit the burden on Trusts and healthcare providers, no reminders are sent.

NACEL of 2020-2021

The 2020 round was cancelled due to COVID-19 pandemic. However, NHS Benchmarking are planning the third round of NACEL to take place in 2021. To date, there are three elements to the NACEL, the quality survey, organisational audit and case note review. A fourth element is being added for the first time to the audit in 2021 which shall consist of a staff review of care at end of life. Outside of those surveyed in previous rounds, bereaved relatives of people who died in mental health inpatient units will be included in the NACEL survey in 2021. The National Audit of Care at the End of Life have highlighted the importance of surveying bereaved relatives in the Quality Survey element of their audit. Given this, the NACEL plan to extend the survey sample timeframe in the 2021 survey to increase response rates.[57]

Table 5 provides an outline of the survey questionnaire used and the response rate for each survey by year of administration Audits commissioned by HQIP 2014-2019 in England [57]:

	2014	2016	2018	2019
Name of Survey tool	CODE	Local Surveys	Quality Survey	Quality Survey
Number included in sample	2,313	n/a	4,390	8,783
Number of respondents	858	n/a	790	1,581
Response Rate	37%	n/a	18%	18%

Table 5: Survey tool, sample, and response rate utilised as part of Audits conducted for HQIP

Outputs and impact

The survey results of National Care of the Dying Audit for Hospitals England and the National Audit of Care at the End of Life (NACEL) are analysed and reported within each audit cycle. The NCADH results were published in a national report with a separately published appendices outlining detail of individual hospital/trust level results.

The NACEL Quality Survey publish results at national level and an individual hospital level on an interactive online site accessible to healthcare providers participating in the Audit only. All hospitals participating in the NACEL are provided with access to an online benchmarking toolkit with a bespoke dashboard against which they are benchmarked in summary score format. The reporting at individual healthcare provider level allows participating hospitals to utilise evidence from their results to develop actions plans to enhance care at end of life. However, the development of quality improvement plans is beyond the scope of NACEL.

Summary of survey questionnaires

The VOICES, CODE and Quality Survey questionnaires ask bereaved relatives about the quality of care their family member received and the level of support they received at the time leading up to the person’s death and thereafter in their bereavement.

Each survey was developed in England and VOICES and CODE have been utilised internationally. All were developed in partnership with bereaved relatives and healthcare professionals to ensure that the important aspects of end-of-life care are addressed within each questionnaire.

Domains of care evaluated within each survey include:

- the control of pain and symptoms other than pain
- psycho-social support which included the emotional well-being of the person and their family and their social support
- spiritual care
- the provision of personal care
- whether the person was treated with dignity and respect
- communication and involvement in decisions
- demographic information about the person that died and the respondent.

Table 6 outlines the different questionnaires utilised for the surveys reviewed including information on the setting, time period, number of questions and domains evaluated.

Survey tool	Setting	Time period assessed	Number of Questions and domains evaluated:
National Survey of Bereaved People (VOICES) 2015	Hospitals (including NHS and non-NHS hospitals), hospices, care homes and the persons' home	Last 3 months and last 2 days	59 questions with free text questions. Domains: Communication, information on care planning, overall experience, pain and symptom management, spiritual and psychosocial care caregiver support, personal care, provision of fluid, nutrition and demographic information including free text questions
CODE (2014)	NHS hospitals	Focussed on Last 2 days	42 questions with free text question Domains: the control of pain and other symptoms, the care provided by doctors and nurses, involvement in decisions and communication, emotional and spiritual support and demographic information
Quality Survey (2019)	NHS acute and community hospitals. From 2021 mental health inpatient units will be included	Last admission to hospital	30 questions including one free text question Domains: symptom management including pain, emotional support, spiritual support, the care provided by staff, communication and the hospital environment.

Table 6 Summary details of survey tool utilised including setting, timing and domains of care evaluated

Key Lessons Learned and Recommendations from England

- Surveying bereaved relatives to enhance end-of-life care has been utilised by the NHS, individual hospitals, hospices and other healthcare providers in England for many years.

- The National Survey of Bereaved People (VOICES), conducted for the first time in 2011 is considered to be the first nationally representative data set that was collected annually, to ascertain the quality of care in all care settings and all causes of death, to inform policy and practice and enhance end-of-life care.

- The National Survey of Bereaved People (VOICES) conducted in England by the Office for National Statistics examined the quality of care in the last 3 months of life in each different setting. 246,752 people received the VOICES Survey in a 5 year period, with 110,311 people responding to the survey, which is an average of 45% response rate.

- Bereaved relatives were identified through the death registration process for the National Survey of Bereaved People (VOICES). Given the high response rate, this proved to be an acceptable method to capture feedback on the experience of care at end of life.

- The National Survey of Bereaved People (VOICES) was evaluated by NHS England and is described as a valuable source of data and useful as a national indicator of end-of-life care. The evaluation also found that an increased sample size with more local level VOICES findings would enhance the ability of healthcare service providers to use findings for service improvement.

- The surveys conducted as part of the National Care of the Dying Audit for Hospitals England and the National Audit of Care at the End of Life were utilised to capture the experience of care at a local healthcare provider level, as part of a wider audit structure commissioned by HQIP on behalf of NHS England.

- The National Audit of Care at the End of Life and National Care of the Dying Audit for Hospitals England Surveys publish individual provider level reports along with national level results. Individual healthcare provider reports allow facilities to see data associated with the care provided by their staff. Reports therefore allow hospitals see results of excellent practice and areas where improvements can be made.

- All surveys reviewed excluded deaths that were sudden and unexpected. The National Survey of Bereaved People (VOICES) used the International Classification of Disease (ICD) codes to exclude those who died suddenly and unexpectedly, thereby minimising the possibility of bereaved relatives from this population receiving a survey.
- Surveying bereaved relatives continues to play a significant role in ascertaining the quality of care at end of life in hospitals as outlined by their continued inclusion in the National Audit of Care at the End of Life and widespread use in healthcare settings such as hospices in England.
- The National Audit of Care at the End of Life emphasise the importance of surveying bereaved relatives in the Quality Survey element of their audit and plan to extend the survey sample timeframe in the 2021 survey to increase response rates.
- Data from the National Survey of Bereaved People (VOICES) and the National Audits is utilised as a means of evaluating and assessing the implementation and compliance to National guidance issued by the National Institute of Health and Care Excellence.[21]

New Zealand

In 2018, there were 33,225 deaths out a total population of 4,699,755 people in New Zealand. Death rates for people aged 65 and over account for 80% of all deaths in 2018.[58] It is projected that by the year 2038 the number of deaths in New Zealand will increase by nearly 50 percent, to around 45,000 each year.[59]

The importance of ascertaining the views of bereaved relatives to improve end-of-life care in New Zealand is recommended in health policy. However, a national survey of bereaved relatives has yet to be undertaken. The following outlines a summary of the policy context and information on two large scale bereaved relatives' surveys to capture perceptions about the quality of care at end of life in New Zealand conducted in collaboration with the individual district health boards.

The information was obtained from a review of the literature including technical reports and journal articles and follow-up communication with the authors and palliative care leads in the respective universities and statutory organisations.

Background

The Ministry of Health is the government's principal advisor on health and disability policy. There are 20 district health boards (DHBs) in New Zealand. Each board is responsible for providing or funding the provision of health services in their district.

The lack of information about patient and whānau/family experiences of and preferences for end-of-life care was identified as a limiting factor in the development of palliative care services in New Zealand. The Ministry for Health published a Review of Adult Palliative Care Services in New Zealand in 2017.[59] The Review recommended a strategic direction for palliative care, aimed at managing future demand on adult palliative care services.

To achieve this aim, the Review outlines actions under five priorities areas:

1. respond to the voices of people with palliative care needs and their families, whānau
2. ensure strong strategic connections
3. improve quality across all settings
4. increase emphasis on primary palliative care
5. grow capability of communities and informal carers.

The Ministry of Health also published the Palliative Care Action Plan in 2017.[60] This action plan focuses on delivering outcomes for 2017–2018 whilst also presenting a broader view of the medium-term to long-term future actions to be taken based on the future projections and growth in demand for palliative care services. The Action Plan identifies each priority as outlined in the Review and what actions need to be taken.

Under the title Priority 1 ‘Respond to the voices of people with palliative care needs and their families and whānau’**.** The Action Plan states:

> ‘Develop a framework for a national survey of patients, family, and whānau from different ethnic and socioeconomic groups about their experiences of adult palliative care. Its aim is to understand what is working well, needs of particular groups and opportunities to improve support, including for iwi and hapū. Build on learnings from piloting of the VOICES survey Frey et al. 2016. As part of the survey, look at equity of access to respite and bereavement care for informal carers across the country – identify and document gaps’ [60]

The Te Arai Palliative Care and End of Life Research Group at the University of Auckland, alongside the Ministry of Health have been tasked with progressing this action.

Objective

Two large scale surveys of bereaved relatives to capture relatives’ perceptions about the quality of care at end of life have been conducted in New Zealand in line with the publication of the Ministry of Health Action Plan that recommended a national survey. The surveys reviewed in this report:

- Survey of Bereaved People (VOICES) conducted in the Auckland District Health Board in 2017. [61]
- VOICES: South Island pilot survey of bereaved people, which surveyed bereaved relatives from the five district health boards on behalf of the South Island Alliance, on the South Island of New Zealand in 2018. [62]

The objectives of both surveys were broadly similar as both wished to:

- report on the end of life experience of people who died, examining the last three months of life, including services provided by general practitioners, hospice, district nursing, urgent care, aged residential care, and inpatient hospital care.

- determine the feasibility of the VOICES questionnaire being adopted as a routine quality improvement measure in the respective District Health Board areas.

Objectives specific to the Auckland District Health Board (ADHB) survey include:

- to identify the nature and extent of physical and psychological symptoms experienced in the last 3 months of life and examine predictors of unmet symptoms
- to identify the proportion of patients accessing community and hospital specialist palliative care services in the last 3 months of life, and to identify predictors of the use of specialist palliative care services
- to explore the overall experience of care delivered in the last 3 months of life from the family/whānau perspective and examine their on-going bereavement related needs
- to focus on the role of ethnicity and culture in determining end of life experience.[61]

Specific objectives of the South Island survey also included looking at the best method of engaging bereaved relatives to take part in this type of survey. [62]

Governance arrangements

The Ministry of Health along with the Te Arai Palliative Care and End of Life Research Group at the University of Auckland, have been tasked with developing a national framework for developing a national survey of bereaved relatives. There have been a number of changes regarding the structures and governance of palliative care within the Ministry of Health. In view of this, the implementation of a national survey of bereaved relatives has yet to be progressed.

Ethical approval

Both surveys emphasised the voluntary nature of participation and an 'opt out reply slip' was enclosed in each survey pack.

The ADHB survey received ethical approval from the University of Auckland's, Human Ethics Committee and also from the District Health Board Hospital research committee. The South Island survey received permission from the Electoral Commission to use the electoral roll to locate postal addresses for bereaved relatives and approval from the University of Canterbury Ethics Committee. Research assistants from the university involved in the latter study signed confidentially agreements. The completed questionnaires were coded and no identifying data used. Data was store according to the universities policies and was only accessible to those working on the survey. The funders of the project did not have access to the data.[64,65]

The survey

The sample

The ADHB survey of bereaved relatives consisted of all adult deaths registered in the period of November 2015 and December 2016. To be included, the person that died must have had a least one contact with the DHB in the previous 12 months e.g. admission to a hospital, outpatient appointment or contact with their GP. Details of the bereaved family member were obtained from the National Health Index (NHI) data base via the district health board. The DHB contact record provided details of the next of kin, relationship to the deceased and postal address.

The South Island VOICES Survey included all adult deaths, regardless if person had contact with the DHB in the previous year.

Exclusions in both studies included those under the age of 18 years old and those where there were incomplete records with no contact details for relatives. Sudden and unexpected deaths were excluded in the Auckland study. However, they were included in the South Island survey as this study did not have access to the NHI data base from all DHB's. This study engaged a company called NoticeMatch and the electoral register to draw up their sample of people who died and also the contact details of bereaved relatives which also included people who died suddenly.

Distribution and Collection

The Auckland DHB survey was distributed by post to bereaved relatives 6 to 12 months following the death of the person. The pack included a letter of invitation, the questionnaire and an opt-out reply slip and a stamped address envelope. A contact phone number was provided for questions or queries about the study. Bereaved relatives were offered the opportunity to participate by completing the questionnaire over the phone or in person. A reminder letter was sent three weeks after the initial posting with another questionnaire and stamped address envelope.[64]

The South Island VOICES Survey deployed similar distribution methods in their study as data collection was initiated no earlier than three months following the person's death. Questionnaires were posted with an invitation letter, stamped address envelope and reply slip. However, it differed as it also gave the option of the person completing the survey online, by telephone, by Skype, face-to-face interview or by returning the completed questionnaire by post. Bereaved relatives were contacted on one occasion in this study.

The South Island survey team put in place a dedicated telephone support line to address queries or concerns of bereaved relatives. The telephone service was identified as an important aspect in the provision and administration of the survey. This service was operated by people with a knowledge of loss, grief and bereavement theory such as social workers, palliative care nurses, counsellors and those with an expertise in supporting bereaved people. Keys skills identified for those operating the service included being comfortable speaking about death, listening to people when upset or while grieving or supporting bereaved people whose family member died suddenly. Bereaved people were offered information and support and referred as appropriate to services within their own area.

Response rate

Of the 3,917 surveys sent to a complete address in the Auckland DHB survey, 826 completed questionnaires a 21% response rate were returned. The majority (90%) of respondents chose to complete the survey themselves with a small number choosing to be interviewed by telephone or a face-to-face interview.[64,61]

The South Island study received 514 completed questionnaires, a 33.4% response rate. [62] The paper questionnaire was the preferred method of responding in this study. Seven respondents chose to use the electronic version via Qualtrics (an online survey tool), and six participants requested face-to-face interviews. Telephone interviews were also requested and completed with members of the research team. The primary reasons for requesting the interviews included wishing to talk through the survey due the fact that the death was sudden.

Table 7 outlines the sample and responses rates for each survey:

	ADHB	South Island
Sample	3,917	1,541.
Complete Responses	826	514
Response rate	21%	33.4%

Table 7 Response rates for VOICES Surveys in New Zealand

Analysis

The Statistical Packages for Social Sciences (SPSS) was utilised for the analysis in both studies of the descriptive statistics. Descriptive analyses explored the characteristics of the deceased person, that of the bereaved person responding and the satisfaction with care across different locations and services. Inferential statistics were used to assess associations between age, diagnosis and location of care, in addition associations with location of care and death. In the South Island study, analysis focused on the descriptive analysis as this research was a pilot study to test the methods rather than a research study to examine possible associations between variables. In the Auckland DHB survey, all inferential statistical analyses were weighted by the age and ethnicity of the total population sampled.[64]

Outputs

The Auckland District Health Board and South Island VOICES Survey have published several peer reviewed journal publications and district level reports on their work which ascertained bereaved relatives views on the quality of care delivered to the person that died and to them in their bereavement.[62-64,74]

The South Island VOICES Survey results has been used in the education and training of staff, specifically focussing on quality improvements. Data from this study was also used for service improvement by the Coroners service and individual healthcare facilities.[65]

Impact

Both VOICES Surveys clearly suggest that the Views of Informal Carers Evaluation of Services (VOICES) survey developed in England and adapted to the New Zealand cultural context is a useful method of collecting information on the quality of care in the last three months of life.

The research team leading the VOICES Survey in ADHB recommended that VOICES be integrated into the ADHB’s suite of new patient experience surveys. Both the Director of Participation and Experience and Manager Patient Experience have indicated they will continue to survey bereaved relatives about their experiences of care at the end of life using VOICES in ADHB.[61]

Both surveys have shown that with some adaption, the feasibility of how the VOICES Survey could be utilised as a national survey to evaluate the provision of care and services from the perspective of bereaved people.

The questionnaire

Both surveys used an adapted version of the Views of Informal Carers Evaluation of Services (VOICES) questionnaire. VOICES is a survey designed to ascertain the views of bereaved relatives on their experiences of care and services in the last three months of life (Office for National Statistics 2016). The VOICES questionnaire was adapted to meet and reflect the cultural context in New Zealand.[62,63,64,74]

This adapted VOICES questionnaire was found to offer a valuable means for gathering data about existing palliative care services. It also identified gaps in the provision of care and was subsequently used by both VOICES surveys in New Zealand to evaluate the quality of palliative and care in the last three months of life.

Key Lessons Learned and Recommendations from New Zealand

- The Ministry of Health identified the lack of information about patient and whānau/ family experiences of and preferences for end-of-life care as a limiting factor in the development of palliative care services in New Zealand and recommends surveying bereaved relatives in the Palliative Care Action Plan report in 2017.
- The VOICES Surveys conducted in Auckland DHB and South Island outlined the feasibility of adapting the VOICES questionnaire to a different cultural context to capture the quality of care from the perspectives of bereaved family members / whanau in New Zealand.
- The VOICES survey of bereaved relatives' questionnaire is recommended as a useful tool in ascertaining the quality of care of the last three months of life in different care settings such as home, nursing home, hospice or hospital.
- Accessing the data sets to survey bereaved relatives in New Zealand was identified as a significant challenge compared to similar surveys conducted in England. Different methodologies to access the data set were adopted in each study. Having access to a standardised data set with the contact details of bereaved relatives was deemed essential in the delivery of a national survey.
- The South Island VOICES Survey team recommended having a telephone service for the duration of the survey to allow participants to ask questions about the survey, complete the survey with a member of the team or access support following receipt of the questionnaire. The team recommended this

service be operated by people with a knowledge of loss, grief and bereavement theory.

- The VOICES surveys in New Zealand were found to be a valuable means for gathering data about existing palliative care services as well as gaps in service provision. Results have been used to improve the quality of care at end of life in healthcare services and the education and training of healthcare staff.
- The Ministry for Health published a ‘Review of Adult Palliative Care Services in New Zealand’ in 2017. The VOICES Surveys provide strong evidence of how one element of this Review can be implemented in practice. A national group consisting of a partnership of all key stakeholders whose responsibility centres on coordinating a national survey and ensuring quality improvements are implemented based on the findings is deemed crucial to implementing the Ministry for Health’s policy to practice.

Japan

In 2015, there were 1.29 million deaths out a total population of 127 million people. People aged 65 and over account for 91 percent of all deaths in Japan. [66]

The national end of life experience surveys reviewed for Japan in this report are the:

- Japan Hospice and Palliative Care Evaluation (J-HOPE) surveys
- National Mortality follow back survey of bereaved relatives conducted in 2018.

The information was obtained from a review of the literature including technical reports, peer reviewed journal articles and follow-up communication and a conference call with the J-HOPE study team based in Tohoku University Graduate School of Medicine.

J-HOPE surveys

Background

The Japan Hospice and Palliative Care Evaluation (J-HOPE) survey was developed to evaluate nationwide hospice and palliative care in all settings including, designated cancer centres, inpatient palliative care units and home hospice care.[67] This review outlines the development and use of the Japan Hospice and Palliative care Evaluation survey which is used to capture relatives' perceptions about the quality of care at end of life in Japan

Two nationwide surveys of bereaved relatives whose family member died as an inpatient in palliative care units were conducted in Japan in 1997 and 2001. Building on this work, the Japan Hospice and Palliative care Evaluation study was developed to ascertain the quality of care provided in the other care settings outside of palliative care units.

The Donabeidan model of structure, process and outcome used for evaluating quality of care underpin the J-HOPE study tools. The Care Evaluation Scale (CES) was developed by Morita et al in Japan to evaluate the process and structure of end-of-life care. The Good Death Inventory (GDI) was developed by Miyashita et al in Japan to evaluate the outcome of end-of-life care. The CES and GDI form the basis of J-HOPE studies to evaluate hospice and palliative care using the Donabeidan model of evaluating care.[68]

Table 8 outlines an overview of the four J-HOPE surveys conducted to date, including the number of institutions and the main outcome measurements undertaken in each study:

	J-HOPE1	**J-HOPE2**	**J-HOPE3**	**J-HOPE4**
Date	**May–August 2007**	**October 2010–April 2011**	**May–July 2014**	**May- June 2018**
Participating institution	56 designated cancer centres, 100 palliative care units (PCUs), 14 home hospices	20 acute hospitals, 103 PCUs, 15 home hospices	20 acute hospitals, 133 PCUs, 22 home hospices	187 institutions (acute hospital, PCUs or home)
Main outcome measurements	Care Evaluation Scale-Short Version, Good Death Inventory-Short Version, Overall Care Satisfaction, Caregiving Consequence Inventory	Care Evaluation Scale-Short Version, Good Death Inventory Short Version, Overall Care Satisfaction	Care Evaluation Scale-Short Version, Good Death Inventory-Short Version, Overall Care Satisfaction, Patient Health Questionnaire 9, Brief Grief Questionnaire	Care Evaluation Scale-Short Version, Good Death Inventory-Short Version, Overall Care Satisfaction, Patient Health Questionnaire 9, Brief Grief Questionnaire, Symptoms patients perceived 1 week before death

Table 8 Overview of J-Hope 1-4 studies [68,70]

The J-HOPE4 study comprised of two elements, as all participants received the short version of the CES and GDI questionnaires for overall quality measurement as outlined in Table 1. The second element of the J-HOPE4 study also included the random assignment of additional questionnaires to participants on a wide range of topics related to the provision of palliative care and care at end of life.

Objective

The J-HOPE survey is part of a national initiative to measure the quality of end of life cancer care in all settings such as home, hospital and hospice inpatient unit.

The main objectives of the J-HOPE survey programme are to evaluate end of life cancer care from the perspective of bereaved relatives. The results are used as a source of performance measure allowing comparison of results from the last places of care focussing on:

- care satisfaction
- structure and process of care
- and achievement of a good death.[67]

The J-HOPE4 survey objectives also set out to:

- examine bereaved family members' self-reported psychosocial conditions, such as grief and depression as bereavement outcomes
- provide date for quality improvement purposes for each participating institution
- provide clinical and academic information concerning the implications of various issues by conducting additional studies.[68]

Governance arrangements

- The provision of palliative care to people who are diagnosed with a life-limiting illness focused on improving the quality of life is underpinned by the National Cancer Act in Japan of 2007. National palliative care programmes in Japan have adopted the measurement of achieving a good death as a quality indicator.
- The J-HOPE programme is a collaboration of palliative care academic experts, working in partnership with healthcare institutions, palliative care teams and Hospice Palliative Care Japan. Participation is voluntary in J-HOPE studies and all members of Hospice Palliative Care Japan are invited to participate. Hospice Palliative Japan commission Tohoku University to manage and oversee the J-HOPE Surveys. Funding for the survey was received from Hospice Palliative Care Japan Foundation and various government grants.[67, 69]

Ethical approval

- Ethical approval for the study was granted by the institutional review boards of Tohoku University Hospital and all participating healthcare institutions. Ethical considerations are a key feature of the J-HOPE study, as people included in the sample were carefully selected to ensure no unnecessary distress was caused by those receiving the survey. Management of the selection process of those to be included or excluded was conducted by the palliative care physician and a nurse in each participating facility. Return of the completed questionnaire was considered as indicating consent to participate in the study.

The survey

The sample

All 463 institutions approved by Hospice Palliative Japan, which included 70 acute hospitals, 337 inpatient palliative care units and 56 home hospice services were invited to participate in the J-HOPE4 study.[68]

Each participating institution identified up to eighty potential respondents that meet the inclusion and exclusion criteria.

The J-HOPE survey was designed to be administered to the person who is most knowledgeable about the care received by the deceased person.

Family members were included in the sample frame if they meet the following criteria:

- person died of cancer
- the deceased person was aged 20 years or older (definition of an adult in Japan)
- bereaved family member is 20 years or older.

Exclusion criteria:

- the patient received palliative care for less than three days
- the bereaved family member cannot be identified
- death was associated with treatment or occurred in an intensive care unit
- the bereaved family member suffered serious psychological distress as determined by the palliative care team
- the bereaved family member is incapable of completing the survey due to health issues such as cognitive impairment as determined by the palliative care team.

Distribution and collection

- The survey was administered by the Secretariat Office in Tohoku University through the participating institutions. The participating institutions send questionnaires directly to bereaved family members for two reasons:
- to ensure compliance with data protection, as no personal data is shared with Tohoku University
- to encourage a greater response as it is believed that bereaved relatives may feel more comfortable if they are mailed directly from institutions.

Data collection was initiated no earlier than three months following the person's death. Questionnaires were posted along with:

- a document to explain J-HOPE's study aims and procedures
- postage paid envelope and a ball point pen as an added incentive to participate.

Respondents are asked to complete and return the questionnaire within 2 weeks. Bereaved family members may opt-out by ticking a 'no participation' box and returning the incomplete questionnaire.

A follow-up letter is sent to all who did not respond to the first questionnaire, approximately one month after the questionnaire was posted.

A survey telephone line is managed by a senior member of the J-HOPE team in Tohoku University for the duration of the study. For J-HOPE3 and J-HOPE4 there were 2-3 calls per day for the duration of the survey. The content of the calls were generally about questionnaire content and very rarely about issues related to bereavement or the burden of receiving the questionnaire. Approximately ten calls were received in J-HOPE4 regarding bereavement related matters. [69]

Response rate

The J-HOPE surveys sample population ranged from 12,787 in 2007 to more than 17,000 bereaved relatives in 2018, with up to 187 palliative care services taking part in 2007, and subsequent years of 2010-11, 2014 and 2018.

Response rates associated with the four J-HOPE surveys conducted to date are outlined in Table 9 below:

	J-HOPE1	J-HOPE2	J-HOPE3	J-HOPE4
Date	**May–August 2007**	**October 2010–April 2011**	**May–July 2014**	**May- June 2018**
Bereaved family members recruited	12,787	13,020	13,584	17,147
Participants and responses	8,398 completed questionnaires for analysis: 2794 responses for designated cancer centres, 5312 for palliative care units (PCUs), 292 for home hospices	7,797 completed questionnaires for analysis: 1279 responses for acute hospitals, 5820 for PCUs, 698 for home hospices	9,126 completed questionnaires for analysis: 814 responses for acute hospitals 7294 for PCUs 1018 for home hospices	9,071 bereaved family members of patients with cancer were recruited from palliative care units, acute hospitals (general ward) and home hospices
Response rate	66%	60%	67%	53%

Table 9 Overview of J-Hope 1-4 studies response rates [68,69,70]

The J-HOPE survey team have examined a number of modes of survey administration and their impact on response rates. In J-HOPE studies, bereaved relatives are not informed in advance of the survey, the first time they learn about the survey is on receipt of the first letter of invitation which includes the survey questionnaire and postage paid envelope. Invitation letters with the option of 'opting in' were used in previous studies and found to have a very low response rate. Therefore, the J-HOPE survey team send the letter of invitation and questionnaires without notification in advance. [69]

In J-HOPE1-3 studies, a reminder was sent which included an envelope and additional questionnaire for those who had not responded to the first mail out. However, in a pilot of the Mortality follow back survey there was no difference in response rates between when an envelope with questionnaire was sent and simple post-card as a reminder. Therefore, the team sent a simple post-card only in both the Mortality follow back survey and J-HOPE4. However, the response rate was lower in J-HOPE4 survey than J-HOPE1-3. Given this and to increase response rates, the J-HOPE survey team plan on sending the questionnaire and envelope again in J-HOPE5 survey to be conducted in 2022.[69]

Analysis

The J-HOPE survey team utilised the computer statistical package SAS (Japanese ver. 9.4; Cary, NC; BMDP, Los Angeles, CA) and the Statistical Package for Social Sciences (SPSS) for the analysis of statistics in this study. Statistical analyses are conducted on various elements of the study including but not limited to examining the characteristics of the participants and place of death, comparisons of overall care satisfaction and the total score of the CES and GDI short versions among places of death. Other analyses includes the response proportions by place of death.

Outputs

The outputs include individual reports to each participating institution comparing the quality of care delivered nationally to the care delivered in their own site. This individual report also provides all responses received from bereaved relatives to open ended questions for their service. The individual reports are developed by the J-HOPE survey team for the purpose of quality improvement.

In addition, the J-HOPE survey team have published several academic peer reviewed journal publications.[67,68,70]

Impact

The four J-HOPE studies were conducted to evaluate hospice and palliative care in terms of processes, structure and outcomes using the Care Evaluation Scale and Good Death Inventory measures. The findings from the four studies report the important issues and trends in the provision of hospice and palliative care to cancer patients in Japan.

A unique and innovative element of the J-HOPE4 study included the random assignment of additional questionnaires to participants on a wide range of topics related to the provision of palliative care and care at end of life. This provided the survey team with very useful data

The survey results provide valuable insights into opportunities for improvement for the various stakeholders involved in the studies and particularly the participating healthcare facilities. [67,68,70] Masukawa 2018 et al note that the J-HOPE studies allowed ‘participating institutions to review the strengths and weaknesses of their daily clinical services’ for the purposes of improving services.[68]

Therefore, J-HOPE studies have not only contributed to quality evaluation in palliative care in Japan, they have also led to quality assurance in each institution.

The J-HOPE survey questionnaires

All J-HOPE study questionnaires contained several outcome measurements as outlined in Table 1. The standard J-HOPE4 questionnaire consisted of 100 questions and it included questions from the short version of the CES and GDI questionnaires and the overall care satisfaction scale question.

The Care Evaluation Scale short version consists of ten items and ten subscales. The questionnaire was designed to ensure that respondents evaluated the structure and process of end-of-life care by rating the need for improvement in the following 10 domains of care:

- help with decision making for patient
- help with decision making for family
- physical care by physician
- physical care by nurse
- psychoexistential care,
- environment
- cost of care
- availability of care
- coordination of care
- and family burden.

Each item is rated on a six-point Likert scale (6: highly agree; 5: agree; 4: somewhat agree; 3: somewhat disagree; 2: disagree; 1: highly disagree). Participants could select “7: N/A” if none of the other scores were applicable to the patient.[71]

The Good Death Inventory (GDI) short version questionnaire was developed in Japan for evaluating the quality of care in the time leading up to a person’s death from cancer.[72] The GDI short version consists of ten core items that Japanese people consistently rate as important and has displayed reliability and validity.

The items in this measure are:

- physical and psychological comfort
- maintaining hope and pleasure
- a good relationship with staff
- not feeling like a burden to others
- maintaining a good relationship with family
- maintaining independence
- environmental comfort
- living in a favourite place
- being respected as an individual
- having a feeling of fulfilment at life completion.

Participant responses to each question in the GDI are on a 7 point Likert scale of ‘absolutely disagree, disagree, somewhat disagree, unsure, somewhat agree, agree and absolutely agree’. The total score is calculated by summing the scores for all items, with a total high score indicating the achievement of a good death.

Another key feature common to all the J-HOPE studies was the aim to ascertain the overall satisfaction with the medical care the patient received at the place of death.

The question asked in each study is ‘Overall, were you satisfied with the medical care the patient received?’ Participant responses to the question are on a 6 point Likert scale of ‘absolutely dissatisfied, dissatisfied, somewhat dissatisfied, somewhat satisfied, satisfied and absolutely satisfied’.

The second element of the J-HOPE4 study also included the possibility of participants receiving additional questionnaires which were randomly assigned to participants on a wide ranging number of topics from assessing spiritual pain, to the care and management of dyspnoea in cancer patients. Topics were chosen to resolve clinical questions identified by the JHOPE4 Survey team. [67,68,70]

National mortality follow back survey of bereaved relatives

Background

A national mortality follow back survey of bereaved relatives was undertaken in 2018 by the National Cancer Centre Japan. The survey was designed to assess the feasibility of conducting a national representative sample population based survey to evaluate the quality of dying and death in Japan.

Objective

The primary objective of the mortality follow back survey of bereaved relatives was to:

- measure the quality of care at end of life for those who died from the leading causes of death in home, hospital and long-term care residential settings
- test the feasibility of using death registration data to survey about care experience at a national level
- examine the respondents' acceptability of this method of survey.

Governance arrangements

The population based national mortality follow back survey is a collaboration of the National Cancer Center Japan, working in partnership with academic experts based in Tohoku University, national agencies and palliative care experts. The survey was conducted by the Division of Medical Support and Partnership within National Cancer Center Japan. The Center was established by the Ministry of Health and Welfare in 1962 and commissioned to lead the nation's cancer treatment, prevention, control programmes, research and education.

Ethical approval

The National Cancer Centre applied to the Ministry of Health, Labour and Welfare for access to mortality data including bereaved relatives contact details and vital statistics to conduct the survey. Ethical approval and scientific validity of this study was confirmed by the National Cancer Center Institutional Review Board in Japan. The study was performed in accordance with the ethical guidelines for epidemiological research issued by the Ministry of Health, Labour, and Welfare. The Ministry facilitated access to mortality data to allow the first population based follow back survey of bereaved relatives.[73]

The survey

The sample

Mortality data was accessed through the national mortality data set collected by the Ministry of Health, Labour and Welfare for people aged over 20 years old and who died in 2016 from one of the following five causes of death, cancer, heart disease, cerebrovascular disease, pneumonia, renal failure. The International Classification of Diseases Codes (ICD codes) were used to get the sample population of the five causes of death for the National Mortality follow back survey. Other criteria included that the person had to be a Japanese national. A representative sample was drawn from this data ensuring that it was representative of three places of death namely, home, hospital and long term care facility. The sample size was increased in anticipation that there would be a 70% non-response rate and a 20% non-delivery rate of postal questionnaires. Therefore, a total sample of 4,812 was selected for this survey.

Distribution and collection

The survey pack was administered by the National Cancer Centre. Data collection was initiated 13-25 months following the person's death due to the availability of data from the Japanese vital statistics agency. Questionnaires were posted along with:

- a document explaining the surveys aims and advising that main caregivers older than 20 years old should respond, the pack also included a postage paid envelope
- a ball point pen as an added incentive to participate was included in a representative sample to test if this incentivised participation.

Respondents are asked to complete and return the questionnaire within one month. Bereaved relatives could opt-out and return the incomplete questionnaire with an explanation if they wish.

Correspondence was sent to all who did not respond to the first questionnaire approximately one month after the questionnaire was posted. An examination of the effect on response rates was conducted by sending a follow-up letter or alternatively a letter with a second questionnaire to a representative sample of bereaved relatives.

Response rate

To heighten awareness about the survey and increase response rates, the National Cancer Centre publicised information about the survey on a number of TV and web news sites. In total 4,812 survey packs were sent to bereaved relatives, with 682 (14.2%) of questionnaires being returned due to an invalid postal address. A total of 2,684 questionnaires were returned which included those who completed the questionnaire or wished to opt-out of the study, giving a response rate of 65%. There were 2,294 completed questionnaires included in the analysis, a response rate of 55.5%

The randomised methods deployed included sending the questionnaire with a pen which resulted in an increased response rate of 7.5%.

The National Mortality follow back survey demonstrated the acceptability of surveying bereaved relatives as 1,946 (84.8%) of the participants agreed with being surveyed to improve the quality of care. Participants were also asked if completing the questionnaire was stressful, with 1,269 (55.3%) indicating it was not stressful and 985 people (42.9%) reporting that responding to the survey led to something good.

Analysis

The survey team utilised the computer statistical package SAS (Japanese ver. 9.4; Cary, NC; BMDP, Los Angeles, CA) for the analysis of statistics in this study. In addition, researchers also used the Statistical Package for Social Sciences (SPSS). Descriptive statistics explored the characteristics of those who died according to disease and also characteristics of bereaved relatives. Statistical analyses were also weighted by the disease rates of the total population sampled from national vital statistics.

Outputs

The team of researchers and palliative care experts within the Division of Medical Support and Partnership from the National Cancer Center Japan have published a number of reports and peer reviewed journal publications associated with the results of National Mortality follow back survey.

Impact

This study demonstrated the acceptability and feasibility of conducting a population-based mortality follow-back survey in Japan. This study was found to have a greater sample representatives than the J-HOPE survey which surveyed people who had utilised specialist palliative care services. A population based survey is recommended as means to assess the quality of care at end of life at a national level. However, a significant drawback of completing a national mortality study compared to the J-HOPE4 study method centres on the fact that that individual reports for quality improvement cannot be created for individual hospitals or hospices for a number of reasons including the :

- difficulty in identifying the different services that the person attended in the days and weeks before the persons death
- Limits associated with a sample size given the large number of healthcare services, such as small clinics, hospitals, nursing homes etc. [69]

The National Mortality feedback survey is a significant addition to the data set regarding care at end of life in Japan enabling the monitoring of national data regarding care at end of life. The results of the Mortality survey identified that improvements need to be made in management of pain management at end of life. This has resulted in the release of designated funding to enhance this area of end-of-life care.[69] The Medical Support and Partnership division within National Cancer Center Japan are committed with its partners to undertaking further National Mortality follow back surveys on an ongoing basis.

The questionnaire

The National Mortality survey questionnaire consisted of 150 questions and similar to the J-HOPE studies, consisted of questions from a number of sources including the:

- Good Death Inventory (GDI) questionnaire to evaluate the quality of dying and death. The GDI measure 18 domains of care that have been identified by Japanese people as important in a good death.
- Care Evaluation Scale questionnaire consisting of 18 domains of care was also used to evaluate the quality of care.
- Caregiver Consequences Inventory was also included to assess caregiver burden.

In addition, the questionnaire included questions on the acceptability of being surveyed with questions such as:

- Do you agree with improving the quality of care through this type of survey?
- Did you feel stressed when answering the questions?
- Did responding to this survey lead you to something good?

The level of agreement for each statement was assessed using a four-point Likert type scale from ‘disagree’ to ‘agree’. The acceptability of the survey was based on answers to the first question and based on 80% or more respondents agreeing with the purpose survey.

Bereaved relatives were also asked to rate:

- The patient’s quality of death and dying in their last month on seven-point Likert scales (1 strongly disagree to 7 strongly agree). Higher values indicated a good death.
- The quality of care in the last place of care on six-point Likert scale (1 strongly disagree to 6 strongly agree). Higher values indicated a higher quality of care.

Other questions included in the questionnaire centred on the circumstances surrounding death and duration of illness. Bereaved relatives were also asked questions about complicated grief and depression.

Key Lessons Learned and Recommendations from Japan

- Nationwide surveys of bereaved relatives to evaluate the quality of care at end of life have been utilised by palliative care providers in hospices, hospitals, and other healthcare providers in Japan for many years.
- The J-HOPE survey comprised all three key elements, namely, the Care Evaluation Scale-Short Version, Good Death Inventory-Short Version, and the Overall Care Satisfaction, which were developed for the measurement of care at end life in Japan.
- The National Mortality follow back survey undertaken by the National Cancer Centre Japan in 2018 demonstrated the acceptability and feasibility of conducting a population-based mortality survey of bereaved relatives to evaluate the quality of dying and death in Japan.
- The National Mortality survey established the acceptability of surveying bereaved relatives to improve the quality of care at end of life with 84.8% of respondents in agreement with being surveyed for this purpose
- The J-HOPE and National Mortality surveys reveal that response rates are increased when a questionnaire and pre-paid envelope is included in the first mail out and also when both are again included in the second mail out.

- The National Mortality survey revealed how response rates could be increased by 7.5% with the inclusion of a pen with the questionnaire.
- A population based survey such as the National Mortality survey is recommended as a method to assess the quality of care at end of life at a national level as it provides access to a representative sample of the population that died.
- The J-HOPE survey included other surveys that were randomly assigned to participants. Conducting additional studies provided the team with significant insights from bereaved relatives addressing various clinical issues.
- One of the significant advantages of the J-HOPE study's methodology is its ability to report national level data and individual hospital or hospice service level data on the quality of care delivered for the purposes of quality improvement.

Conclusion

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

Next steps

The National Care Experience Programme will use the methodology outlined in this paper to inform the development of the National End of Life Survey for Ireland.

Appendix 1: National context of end of life surveys in Ireland

Background

National reports, guidance and policy documents recognise the importance of the provision of good care at end of life in Ireland.[1-4] Recent reports indicate that there is an increasing concern about the quality of palliative and end-of-life care provided in acute hospitals. Several reports have highlighted significant deficits and poor care provided to dying patients and their families in this setting.[5-9] Other studies in Ireland, highlight many areas of good practice whilst indicating improvements that could be made to enhance care at end of life in hospitals.[10,11]

To date, surveys of bereaved relatives in Ireland have been undertaken by individual service providers such as hospitals or hospices on standalone basis or through a collaboration of the voluntary and state healthcare service providers and academic partners.[10-14]

Assessing and measuring the experience and quality of care provided is a key component of healthcare systems. However, there is no standardised national approach in Ireland to capturing the experience of care of those who have died and that of their relatives.[10,11]

Policy context

The National End of Life Survey (NELS) is being developed within the context of government and health policy, and research which has endorsed engaging bereaved relatives to improve the quality of care delivered by health and social care staff. The Survey will provide important insights into the experiences of care delivered by healthcare services at end of life and will fulfil the requirement of healthcare services to ensure they are providing high-quality care as set out in:

- Our Shared Future - programme for government (2020) [15]
- HIQA Corporate Plan 2019-2021[16]
- HIQA Business Plan 2020 [17]
- HSE National Clinical Care Programme for Palliative Care, Model of Care (2019) [18]
- HSE Palliative Care Services: Three Year Development Framework (2017-2019) [19]
- HSE National Healthcare Charter (2012) [20]
- HIQA National Safer Better Healthcare Standards (2012) [21]

The NESC review titled Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals [22] acknowledged the importance of service user engagement to improve care at end of life.

HIQA published the National Standards for Safer Better Healthcare in 2012 to provide a national and consistent approach to improving safety, quality and reliability in the health service. The HSE National Clinical Programme for Palliative Care published in 2014 a number of workbooks associated with meeting the HIQA Standards. The Effective Care and Support: Quality Assessment and Improvement Workbook [23] makes a number of recommendations to meet the HIQA Standards including seeking feedback from service users and relatives to inform 'improvement plans'. This workbook also suggests that the delivery of palliative care should be evaluated by ascertaining feedback from relatives.

The Finite Lives report which examines State Services around dying, death and bereavement proposed the State conduct a national dialogue of end of life issues and noted the importance of engaging in a 'listening exercise to learn about people's direct experience of end of life'. [24]

The Survey of Bereaved Relatives: VOICES MaJam (the largest survey of bereaved relatives undertaken in two acute hospitals in Ireland to date), recommended based on their experience, the surveying of bereaved relatives at a national level for the purposes of quality improvement.[11]

The Ombudsman speaking at the launch of A Good Death: Progress Report in 2018 asserted that 'in addition to complaints, hospital surveys (such as the Survey of Bereaved Relatives: Voices MaJam in 2017) of bereaved relatives also provide insight into the experience of families and can lead to improved standards of care'. [2] The Ombudsman strongly endorsed the importance of surveying bereaved relatives in this report stating 'hospital specific surveys of this nature provide excellent real time insight into all aspects of end of life services. Crucially, they provide hospitals with vital information about shortcomings in service delivery. As a result, I would encourage all health service providers to undertake regular surveys of this kind'.[3]

Surveying bereaved relatives is recommended as a means of evaluating the experience of care delivered as outlined in the HSE National Clinical Care Programme for Palliative Care, Model of Care (2019).[18] The recommendation of surveying bereaved relatives is outlined in the metrics section of this report. Specifically, there is a commitment to measure the quality of life and death through surveying bereaved relatives with a view to having 'an improved patient experience and better quality of life and death'. The model of care also suggests surveying bereaved relatives to ascertain if people are 'cared for in a place of care that is acceptable to them and their families'.

Sláintecare, the cross-party strategy for health reform in Ireland advocates the use of standardised national experience surveys to inform improvements and shape policy.[27]

The programme for government, entitled Our Shared Future published in June 2020 is committed under the heading 'More Compassionate Care' to ensuring 'patients' voices are heard'. The programme specifically under the title 'End of Life Care' commits to developing end of life services, noting 'the care and dignity of a dying person and their family must be our focus'.[15]

National Care Experience Programme

The National Care Experience Programme gathers data on people's experiences of health and social care in a systematic, consistent and reliable way.

The success of the National Inpatient Experience Survey led to requests for surveys across a range of other healthcare areas, including maternity care and end-of-life care in line with commitments in national strategies, HIQAs Corporate Plan 2019-2021 and HIQA's Business Plan for 2020.[16,17]

HIQAs Corporate Plan 2019 – 2021 and Business Plan 2020 commits to delivering:

- a roadmap for the National Care Experience Programme and implemented a prioritisation process for future programmes of work
- measured people's experiences of acute inpatient care, maternity services and two further prioritised services, and reported our findings to the public

The National Care Experience Programme Strategic Plan 2019-2021 states that it will 'publicly report on acute inpatient care, maternity services, and two other prioritised areas in a timely and accessible manner, and communicate the actions arising from the findings of the surveys'.[25]

In June 2019, the NCEP Steering Group selected care at end of life as one of the two areas to be surveyed. It was selected as a result of the implementation of the prioritisation criteria by the NCEP Steering Group, which reflected the priorities within each of the partner organisations.

HIQA's 2020 Business Plan Objective 3.04 outlines that under the governance of the NCEP Steering Group, the NCEP commits to commencing the development of the model and methodology for an end-of-life care survey in 2020.[17]

The National Public Health Emergency Team for COVID-19 and NCEP

The National Public Health Emergency Team (NPHET) for COVID-19 was established on 27th January 2020 in the Department of Health and is chaired by the Chief Medical Officer. The NPHET oversees and provides national guidance, direction, support and expert advice on the development and implementation of a strategy to contain COVID-19 in Ireland.

The NPHET recommended the establishment of an Expert Panel on Nursing Homes, to examine the complex issues surrounding the management of COVID-19 among this particularly vulnerable cohort including issues related to mortality and excess mortality in the period of March, April and May 2020. The COVID-19 Expert Panel Final Report was published in July 2020 and made a number of recommendations including that the 'National Care Experience Programme work to include expansion to nursing home residents should be progressed at pace.' [26] The Programme is therefore progressing work on the development of the National End of Life Survey to include people who were cared for and died in nursing homes.

The National End of Life Survey aims to establish the quality of healthcare delivered by our health and social care services. The findings will inform quality improvement within our service providers, national standards and monitoring programmes in the national regulator, Health Information and Quality Authority, and national policy and legislation in the Department of Health. The survey when developed will invite bereaved relatives to share their experience about the care received in the last months of life and in doing so inform the health and social care professionals about what is important in the provision of care at this time.

The NCEP is currently developing the model and methodology to implement the National End of Life Survey which will be informed by this international review of surveys.

References for Appendix 1

1 Department of Health and Children. Report of the National Advisory Committee on Palliative Care. 2001

2 Office of the Ombudsman. Speech by the Ombudsman at the launch of A Good Death: Progress Report. 2018. Available from: https://www.ombudsman.ie/news/ombudsman-launches-a-good/

3 Office of the Ombudsman. A Good Death: Progress Report. Dublin: Office of the Ombudsman; 2018. Available from: https://www.ombudsman.ie/publications/reports/a-good-death-progress-rep/GoodDeathProgressWeb.pdf

4 HSE. National Clinical Care Programme for Palliative Care. Palliative Care Needs Assessment Guidance. 2016.

5 Francis R. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. London: The Stationery office; 2013. Available from: http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com/report

6 Neuberger J. More Care, Less Pathway: A Review of the Liverpool Care Pathway London: Department of Health; 2013. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

7 Royal College of Physicians. End of Life Care Audit-Dying in Hospital: National Report for England. London: Royal College of Physicians; 2016. Available from: https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016

8 Parliamentary and Health Service Ombudsman. Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. London: Parliamentary and Health Service Ombudsman. 2015. Available from: https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf

9 Office of the Ombudsman. A Good Death: A Reflection on Ombudsman Complaints about End of Life Care in Irish Hospitals. Dublin: Office of the Ombudsman; 2014. Available from: https://www.ombudsman.ie/publications/reports/a-good-death/A-Good-Death-Report.pdf

10 McKeown K, Haase T, Pratschke J, Twomey S, Donovan H, Engling F. National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9. Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life. Dublin: Irish Hospice Foundation; 2010. Available from: http://hospicefoundation.ie/wp-content/uploads/2013/04/FINAL_National_Audit_of_End_of_Life_Care_in_Hospitals_Report_5.pdf

11 Ó Coimín D, Korn B, Prizeman G, Donnelly S, Hynes G, Curran M, Codd M. Survey of Bereaved Relatives: VOICES MaJam. Dublin: Mater Misericordiae University Hospital and St. James's Hospital; 2017. Available from: https://www.lenus.ie/handle/10147/621493

12 Association for Palliative Medicine of Great Britain and Ireland. FAMCARE 2018 Bereaved relatives' satisfaction with specialist palliative care services: A service evaluation by the Association for Palliative Medicine of Great Britain and Ireland; 2018. Available from: https://apmonline.org/wp-content/uploads/2019/02/famcare-final-report-2018.pdf

13 Ó Coimín D, Prizeman G, Korn B, Donnelly S, Hynes G. Dying in acute hospitals: voices of bereaved relatives. BMC Palliative Care. 2019;18(1):91. DOI https://doi.org/10.1186/s12904-019-0464-z

14 Higginson I, Yi D, Johnston B, Ryan K, McQuillan R, Selman L, et al. Associations between informal care costs, care quality, carer rewards, burden and subsequent grief: the international, access, rights and empowerment mortality follow-back study of the last 3 months of life (IARE I study). BMC Medicine. 2020;18. DOI https://doi.org/10.1186/s12916-020-01768-7

15 Programme for Government. Our Shared Future. June 2020. Available from: https://aoep.ie/wp-content/uploads/2020/06/2020-06-15-ProgrammeforGovernment_Corrected-Final-Version.pdf

16 HIQA. HIQA Corporate Plan 2019-2021. 2019. Available from: https://www.hiqa.ie/reports-and-publications/corporate-publication/corporate-plan-2019-2021

17 HIQA. HIQA Business Plan 2020. 2020. Available from: https://www.hiqa.ie/sites/default/files/2020-12/Business-Plan-2020.pdf

18 HSE National Clinical Programme for Palliative Care. HSE Adult Palliative Care Services Model of Care for Ireland. 2019.

19 HSE. Palliative Care Services: Three Year Development Framework (2017-2019). 2017. Available from: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/palliative-care-services-development-framework.pdf

20 HSE. National Healthcare Charter. 2012.

21 HIQA. National Safer Better Healthcare Standards. 2012. Available from: https://www.hiqa.ie/sites/default/files/2017-01/Safer-Better-Healthcare-Standards.pdf

22 National Economic and Social Council. Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals. Dublin: National Economic and Social Council; 2012. Available from: http://www.nesc.ie/en/publications/publications/nesc-reports/quality-and-standards-in-human-services-in-ireland-end-of-life-care-in-hospitals/

23 HSE National Clinical Programme for Palliative Care. Effective Care and Support: Quality Assessment and Improvement Workbook. 2014. Available from: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/workbook-2-effective-care-and-support.pdf

24 O’ Donnell, M.L. Finite Lives: Dying Death and Bereavement an examination of State Service in Ireland. 2017. Available from:

http://marielouiseodonnell.ie/wp-content/uploads/2017/05/Marie-Louise-ODonnell-Finite-Lives.pdf

25 National Care Experience Programme. National Care Experience Programme Strategic Plan 2019-2021. 2019. Available from: https://yourexperience.ie/about/news/national-care-experience-programme-strategic-plan-2019-2021/

26 Department, of, Health. COVID-19 Nursing Homes Expert Panel Examination of Measures to 2021. Report to the Minister for Health. 2020. Available from: https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/

27 Department of Health. Sláintecare Action Plan 2019. Dublin, Department of Health; 2019. Available from: https://assets.gov.ie/9379/05384619bb2240c18c294b60578117e1.pdf

Appendix 2: Organisations and participants that contributed to this review

The Project Lead on behalf of 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. The organistations and contributors to this review are outlined in Table 10:

Country	Organisation	Type of Organisation	Title
United States of America	Center for Medicare	Government agency	Survey Manager, Division of Consumer Assessment and Plan Performance
New Zealand	University of Canterbury	Academic	Senior Academic and Head of Research
	University of Auckland	Academic	Senior Academics, Head of Research and Director of National Palliative Care
	Health Quality & Safety Commission	Regulator of health and social care services	Advance Care Planning Promotions Coordinator
	South Island Alliance	Government health agency	Regional Programme Facilitator - Palliative Care
England	NHS	Government health agency	Survey Programme Manager
Japan	Tohoku University	Academic	Senior Academics, Head of Research and Director of National Palliative Care Research Programme

Table 10: Organisations and contributors to review.

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;3:e001570. doi:10.1136/bmjopen-2012-001570

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, Department of Health Statement of Strategy 2016-2019. 2016. Available from: https://health.gov.ie/wp-content/uploads/2016/12/DoH-SoS-2016-2019-Final-En.pdf

8. Creating a better future together. The National Maternity Strategy, 2016-2026. 2016. Available from: https://health.gov.ie/wp-content/uploads/2016/01/Final-version-27.01.16.pdf

9. The National Cancer Strategy, 2017-2026. 2017. Available from: https://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf

10. Department of Health. Sláintecare Implementation Strategy. 2016. Available from: https://health.gov.ie/wp-content/uploads/2018/08/Sl%C3%A1intecare-Implementation

11. National Care Experience Programme. National Patient Experience Survey. 2017. Available from: https://yourexperience.ie/wp-content/uploads/2019/07/NPES-National-Report-2017-WEB.pdf

12. Health Services Executive. HSE Listening, Responding and Improving. The HSE response to the findings of the National Patient Experience Survey.

2018. Available from: https://www.patientexperience.ie/app/uploads/2018/11/NPES_National_QIP_2018.pdf

13. HSE National Clinical Programme for Palliative Care. Effective Care and Support: Quality Assessment and Improvement Workbook. 2014. Available from: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/workbook-2-effective-care-and-support.pdf

14. Office of the Ombudsman. Speech by the Ombudsman at the launch of A Good Death: Progress Report. 2018. Available from: https://www.ombudsman.ie/news/ombudsman-launches-a-good/

15. Office of the Ombudsman. A Good Death: Progress Report. Dublin: Office of the Ombudsman; 2018. Available from: https://www.ombudsman.ie/publications/reports/a-good-death-progress-rep/GoodDeathProgressWeb.pdf

16. HSE National Clinical Care Programme for Palliative Care. Model of Care. 2019. Available from: https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2019/04/NCP-Palliative-Care-Model-of-Care-24.04.0219.pdf

17. Ó Coimín D, Korn B, Prizeman G, Donnelly S, Hynes G, Curran M, Codd M. Survey of Bereaved Relatives: VOICES MaJam. Dublin: Mater Misericordiae University Hospital and St. James's Hospital; 2017. Available from: https://www.lenus.ie/handle/10147/621493

18. McKeown K, Haase T, Pratschke J, Twomey S, Donovan H, Engling F. National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9. Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life. Dublin: Irish Hospice Foundation; 2010. Available from: http://hospicefoundation.ie/wp-content/uploads/2013/04/FINAL_National_Audit_of_End_of_Life_Care_in_Hospitals_Report_5.pdf

19. Association for Palliative Medicine of Great Britain and Ireland. FAMCARE 2018 Bereaved relatives' satisfaction with specialist palliative care services: A service evaluation by the Association for Palliative Medicine of Great Britain and Ireland; 2018. https://apmonline.org/wp-content/uploads/2019/02/famcare-final-report-2018.pdf

20. NHS England. Consultation Report: Feedback on the Quality of End of Life Care. 2016. Available from: https://www.england.nhs.uk/wp-content/uploads/2016/04/voices-consultation-summary.pdf

21. Centers for Disease Control and Prevention 2020, Mortality in the United States,2018. Available from: https://www.cdc.gov/nchs/products/databriefs/db355.htm

22. United States Census Bureau 2020 Available from: https://www.census.gov/quickfacts/fact/table/US/IPE120218

23. U.S. Centers for Medicare & Medicaid Services. CAHPS Hospice Survey. Available from: https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/CAHPS-Hospice-Survey

24. CAHPS® Hospice Survey Quality Assurance Guidelines Version 7.0. 2020. Available from: https://hospicecahpssurvey.org/globalassets/hospice-cahps/quality-assurance-guidelines/cahps-hospice-survey-quality-assurance-guideline-v7.0-september-2020.pdf

25. Centers for Medicare & Medicaid Services,CAHPS Hospice Survey development. 2014. Available from: https://hospicecahpssurvey.org/globalassets/hospice-cahps/home-page/hospice_field_test_report_2014.pdf

26. Price R., et al. Hospice Experience of Care Survey Development and Field Test Research report. Santa Monica, CA: RAND Corporation, 2014. https://www.rand.org/pubs/research_reports/RR657.html.

27. Centers for Medicare & Medicaid Services, CAHPS Scoring and Analysis. 2019. Available from: www.hospicecahpssurvey.org/en/scoring-and-analysis

28. Agency for Healthcare Research and Quality. CAHPS Hospice Survey. Content last reviewed June 2019. Rockville, MD. 2020. Available from: https://www.ahrq.gov/cahps/surveys-guidance/hospice/index.htm

29. Dean-Whittaker D., Centers for Medicare & Medicaid Services. CAHPS Hospice Survey. Video conference call to Ó Coimín D., and O’ Carroll T. October 2020. National End of Life Survey, National Care Experience Programme. HIQA. Dublin.

30. Centers for Medicare & Medicaid Services, CAHPS Hospice Survey FAQ. June 2020. Available from: https://hospicecahpssurvey.org/globalassets/hospice-cahps/home-page/cahps_hospice_survey_fact_sheet_june-2020.pdf

31. National Hospice and Palliative Care Organization. CAHPS Hospice Survey. Available from: https://www.nhpco.org/regulatory-and-quality/quality/hospice-quality-reporting-program-hqrp/cahps-hospice-survey/

32. Centers for Medicare & Medicaid Services, CAHPS Hospice Survey tool. 2019. Available from: https://hospicecahpssurvey.org/globalassets/hospice-cahps/survey-instruments/english/cahps-hospice-qag-v6.0-english-mail---september-2019rev.pdf

33. Korb, L., Caring for U.S. Veterans: A Plan for 2020. Centre for American Progress. Available from: https://www.americanprogress.org/issues/security/reports/2019/12/04/478034/caring-u-s-veterans-plan-2020/

34. Thorpe JM, Smith D, Kuzla N, Scott L, Ersek M. Does Mode of Survey Administration Matter? Using Measurement Invariance to Validate the Mail and Telephone Versions of the Bereaved Family Survey. J Pain Symptom Manage. 2016;51(3):546-56. Available from: https://doi.org/10.1016/j.jpainsymman.2015.11.006

35. US Department of Veterans Affairs. The Veteran Experience Center Methods; 2020. Available from: https://www.cherp.research.va.gov/PROMISE/index.asp

36. Kutney-Lee, A., Brennan, C. W., Meterko, M., & Ersek, M. (2015). Organization of nursing and quality of care for veterans at the end of life. Journal of pain and symptom management, 49(3), 570–577. Available from: https://doi.org/10.1016/j.jpainsymman.2014.07.002

37. Gray C, Yefimova M, McCaa M, Goebel JR, Shreve S, Lorenz KA, et al. Developing Unique Insights From Narrative Responses to Bereaved Family Surveys. Journal of Pain and Symptom Management. 2020;60(4):699-708. Available from: http://www.sciencedirect.com/science/article/pii/S0885392420303833

38. Veterans Health Administration Fiscal Year 2017 Annual Report. 2017. Available from: https://www.va.gov/HEALTH/docs/VHA_AnnualReport_FY2017.pdf

39. Office for National Statistics. Statistical bulletin, Deaths registered in England and Wales: 2019. 2020. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2019#main-points

40. Royal College of Physicians End of Life Care Audit – Dying in Hospital National Report for England 2016. London: Royal College of Physicians; 2016.

41. Association for Palliative Medicine of Great Britain and Ireland. FAMCARE 2019 Bereaved relatives' satisfaction with specialist palliative care services: A service evaluation by the Association for Palliative Medicine of Great Britain and Ireland; 2019. https://apmonline.org/wp-content/uploads/2020/05/FAMCARE-National-Data-Report.pdf

42. Hunt KJ, Richardson A, Darlington AE, Addington-Hall JM. Developing the methods and questionnaire (VOICES-SF) for a national retrospective mortality follow-back survey of palliative and end-of-life care in England. BMJ Support Palliative Care. 2019;9(1):e5.

43. Office for National Statistics. National Bereavement Survey (VOICES) Quality Methodology and Information (QMI) Report. London: Office for National Statistics 2016.

44. Office for National Statistics. National Survey of Bereaved People (VOICES) 2014 London; 2015.

45. Hunt KJ, Addington-Hall J. A toolkit for the design and planning of locally-led VOICES end of life care surveys. Southampton: University of Southampton; 2011.

46. Hunt KJ, Shlomo N, Richardson A, JM A-H. VOICES Redesign and Testing to Inform a National End of Life Care Survey. 2011.

47. Department of Health. First national VOICES survey of bereaved people: key findings report. London; 2012.

48. National Institute for Health and Care Excellence. Impact End of Life Care for Adults 2020. London: NICE; 2020.

49. Houses of Commons. Parliamentary Question National Survey of Bereaved People: Written question - 158729. London: Houses of Parliament 2018.21.

50. Healthcare Quality Improvement Partnership announce that the National Audit of Care at the End of Life (NACEL) contract has been awarded to the NHS Benchmarking Network [press release]. London: Healthcare Quality Improvement Partnership. 26 September 2017. Available on: https://www.hqip.org.uk/news/national-audit-for-care-at-the-end-of-life-nacel-contract-has-been-awarded-to-the-nhs-benchmarking-network/#.XypgD25Fw2w

51. Royal College of Physicians. End of Life Care Audit – Dying in Hospital National Report for England 2016. London: Royal College of Physicians; 2016.

52. NHS Benchmarking Network. National Audit of Care at the End of Life: First round of audit report England and Wales. 2019.

53. NHS Benchmarking Network. Fair Processing Notice. London: NHS Benchmarking Network; 2019.

54. NHS Benchmarking Network. National Audit of Care at the End of Life: Second round of the audit (2019/20) report England and Wales. Health Quality Improvement Partnership; 2020.

55. Royal College of Physicians. National care of the dying audit for hospitals, England 2014. London: Royal College of Physicians; 2014.

56. NHS Benchmarking Network. Network NB. National Audit of Care at the End of Life First round of the audit (2018/19) report England and Wales. London: NHS Benchmarking Network; 2019.

57. Hibbert, D., NHS Benchmarking Network. Conference call to Ó Coimín D., Project Lead and O' Carroll T. Programme Manager. 2 December 2020. National End of Life Survey, National Care Experience Programme. HIQA. Dublin. 2020.

58. Stats NZ. Births and Deaths 2018. Available from: https://www.stats.govt.nz/information-releases/births-and-deaths-year-ended-december-2018

59. Ministry of Health, Review of Adult Palliative Care Services in New Zealand. 2017. Available from: https://www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand

60. Ministry of Health, Palliative Care Action Plan, Wellington: Ministry of Health. 2017. Available from: https://www.health.govt.nz/system/files/documents/publications/palliative-care-action-plan_0.pdf

61. Gott M., Old A., What are the end of life circumstances of patients dying under the care of the Auckland District Health Board? Auckland Academic Health Alliance. 2019.

62. Reid K., Kirk R, Barnett P., Richardson A., Ahuriri-Driscoll A., VOICES: South Island pilot survey of bereaved people. The New Zealand Medical Journal Vol 133 No 1518: 17 July 2020. Available from: https://www.nzma.org.nz/journal-articles/voices-south-island-pilot-survey-of-bereaved-people

63. Frey R., Williams L., Trussardi G., et al. 2016. The views of informal carers' experiences of services (VOICES): towards an adaptation for the New Zealand bicultural context. BMJ Supportive and Palliative Care. Available from: DOI: https://doi.org/10.1017/S1478951516000146

64. Frey R., Robinson J., Andrew Old A., Raphael D., Gott M., Factors associated with overall satisfaction with care at the end-of-life: Caregiver voices in New Zealand Health and social care in the community first published: 21 June 2020. Available from: https://doi.org/10.1111/hsc.13053

65. Reid K., VOICES: South Island pilot survey of bereaved people. Video conference call to Ó Coimín D., and O' Carroll T. 13 October 2020. National End of Life Survey, National Care Experience Programme. HIQA. Dublin. 2020

66. National Institute of Population and Social Security Research Population Vital Statistics. 2017. Available from: http://www.ipss.go.jp/pr-ad/e/eng/03.html

67. Miyashita M, Morita T, Sato K, Tsuneto S, Shima Y. A Nationwide Survey of Quality of End-of-Life Cancer Care in Designated Cancer Centers, Inpatient Palliative Care Units, and Home Hospices in Japan: The J-HOPE Study. Journal of Pain and Symptom Management. 2015;50(1):38-47.e3.

68. Masukawa K, Aoyama M, Morita T, Kizawa Y, Tsuneto S, Shima Y, et al. The Japan hospice and palliative evaluation study 4: a cross-sectional questionnaire survey. BMC Palliative Care. 2018;17(1):66.

69. Miyashita M, Aoyama M,. The Japan hospice and palliative evaluation study and surveys of bereaved family members in Japan. Video conference call to Ó Coimín D., and O'Carroll T. 19 November 2020. National End of Life Survey, National Care Experience Programme. HIQA. Dublin. 2020

70. Mori M, Morita T, Imai K, Yokomichi N, Yamaguchi T, Masukawa K, et al. The Bereaved Families' Preferences for Individualized Goals of Care for Terminal Dyspnea: What Is an Acceptable Balance between Dyspnea Intensity and Communication Capacity? Palliative Medicine Reports. 2020;1(1):42-9.

71. Miyashita M, Aoyama M, Nakahata M, Yamada Y, Abe M, Yanagihara K, et al. Development the Care Evaluation Scale Version 2.0: a modified version of a measure for bereaved family members to evaluate the structure and process of palliative care for cancer patient. BMC palliative care. 2017;16(1):8-.

72. Hasegawa T, Sekine R, Akechi T, Osaga S, Tsuji T, Okuyama T, et al. Rehabilitation for Cancer Patients in Inpatient Hospices/Palliative Care Units and Achievement of a Good Death: Analyses of Combined Data From Nationwide Surveys Among Bereaved Family Members. J Pain Symptom Manage. 2020;60(6):1163-9.

73. Nakazawa Y, Takeuchi E, Miyashita M, Sato K, Ogawa A, Kinoshita H, et al. A Population-Based Mortality Follow-Back Survey Evaluating Good Death for Cancer and Noncancer Patients: A Randomized Feasibility Study. Journal of Pain and Symptom Management. 2020.

74. South Island Alliance Programme Office. Statistical Bulletin: VOICES South Island Pilot Survey of Bereaved People 2017. 2020. Available from: https://www.sialliance.health.nz/programmes/palliative-care/useful-resources/

National Care Experience Programme

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Seirbhís Sláinte Níos Fearr á Forbairt | Building a Better Health Service

An Roinn Sláinte
Department of Health

Irish Hospice Foundation

This work is proudly supported by Irish Hospice Foundation