

National Bereavement Survey (VOICES), 2011

Coverage: England

Date: 03 July 2012

Geographical Area: Country

Theme: Health and Social Care

Key findings

- The National Bereavement Survey (VOICES) 2011 achieved a response rate of 45.7 per cent, a comparable response rate to other postal surveys of the bereaved exploring end of life care
- The overall quality of care across all services in the last three months of life was rated by respondents: 12 per cent as outstanding, 30 per cent as excellent, 33 per cent as good, 14 per cent as fair and 10 per cent as poor
- Being shown dignity and respect by staff was highest in hospices (87 per cent 'all the time' for hospice doctors and 80 per cent for hospice nurses) and lowest in hospitals (57 per cent 'all the time' for hospital doctors and 48 per cent for hospital nurses)
- For those who expressed a preference, the majority preferred to die at home (71 per cent), although the most commonly recorded place of death was a hospital (53 per cent)

Summary

The National Bereavement Survey (VOICES) was commissioned by the Department of Health and administered by the Office for National Statistics (ONS). The End of Life Care Strategy published by the Department of Health in July 2008 set out a commitment to promote high quality care for all adults at the end of life and stated that outcomes of end of life care would be monitored through surveys of bereaved relatives (Department of Health, 2008).

This Statistical Bulletin describes the methods and summarises the key results of the first national survey of the bereaved. Full results with confidence intervals are available in an [accompanying reference table](#).

The [main report for this first national survey](#) is published on the [Department of Health website](#). It presents findings according to the following themes: quality of care; coordination of care; relief of

pain and suffering; care and support for the patient; decision making, communication, preferences and choice; and support for relatives, friends and carers. It also contains some benchmarking charts which show variations by PCT cluster.

Results

Results are presented with confidence intervals, to aid interpretation. Confidence intervals are useful for indicating the amount of uncertainty there is around a figure and for allowing comparison of groups or areas.

All [results tables for the 2011 VOICES survey](#) can be downloaded from the ONS website.

Quality of Care

Ratings of the overall quality of care across all services in the last three months of life were reported by most respondents (84 per cent). Of these 12 per cent rated the care as outstanding, 30 per cent as excellent, 33 per cent as good, 14 per cent as fair and 10 per cent as poor: see table for 'Overall quality of care'.

Figure 1. Ratings of overall quality of care across all services in the last three months of life



Source: Office for National Statistics

Download chart

[XLS](#) [XLS format](#)

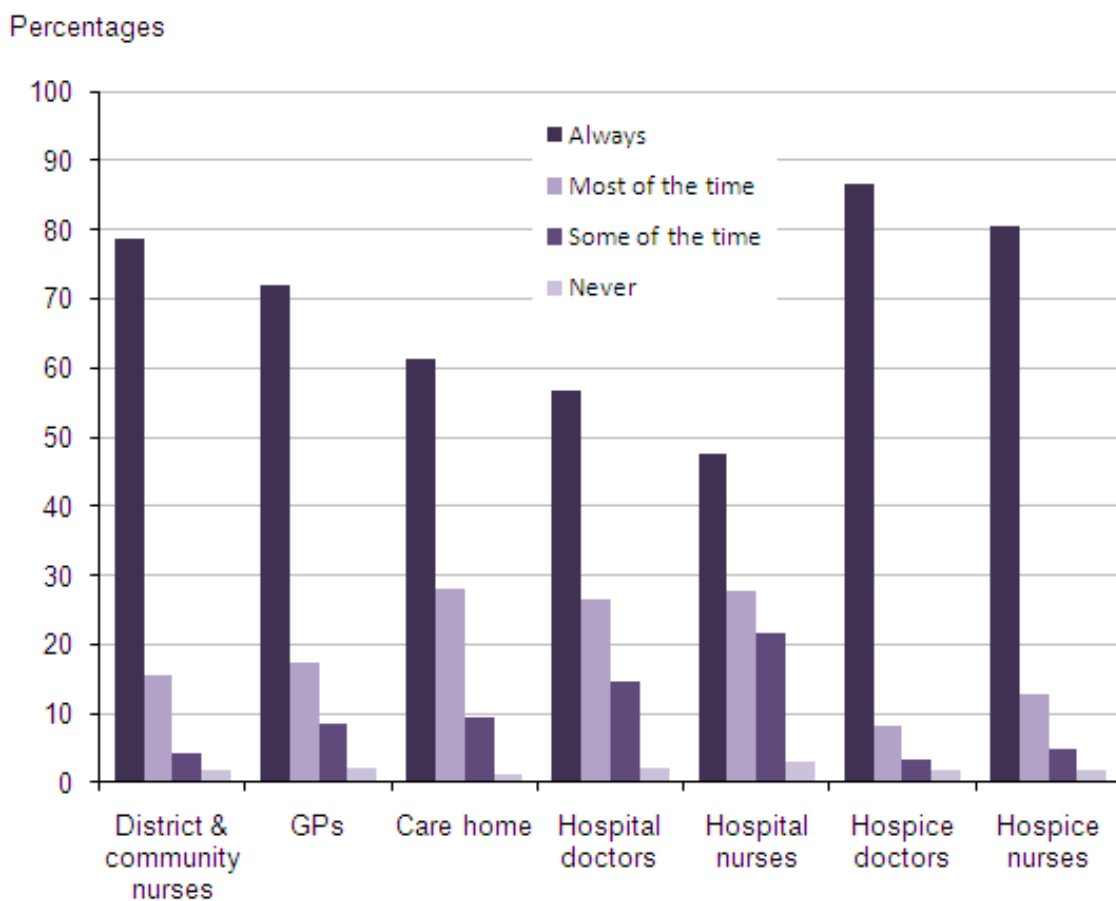
(26.5 Kb)

Further details of quality of care by setting or service and by cause of death and age at death are available: see tables for 'Quality of care 3 months'.

Dignity and Respect

Another aspect of care was whether staff treated the patient with dignity and respect. Staff in hospices received the highest proportion showing dignity and respect 'all of the time' (87 per cent for hospice doctors and 80 per cent for hospice nurses). Hospital staff received the lowest proportion showing dignity and respect all of the time (57 per cent for hospital doctors and 48 per cent for hospital nurses).

Figure 2. How often the patient was treated with dignity and respect in the last three months: by setting or service provider



Source: Office for National Statistics

Download chart

[XLS](#) [XLS format](#)

(27 Kb)

Further details of responses related to dignity and respect reported by the different care settings and services for the last three months and for the last two days of life, and by cause of death and age at death: see tables 'Dignity and Respect 3 months' and 'Dignity and Respect 2 days'.

Coordination of care

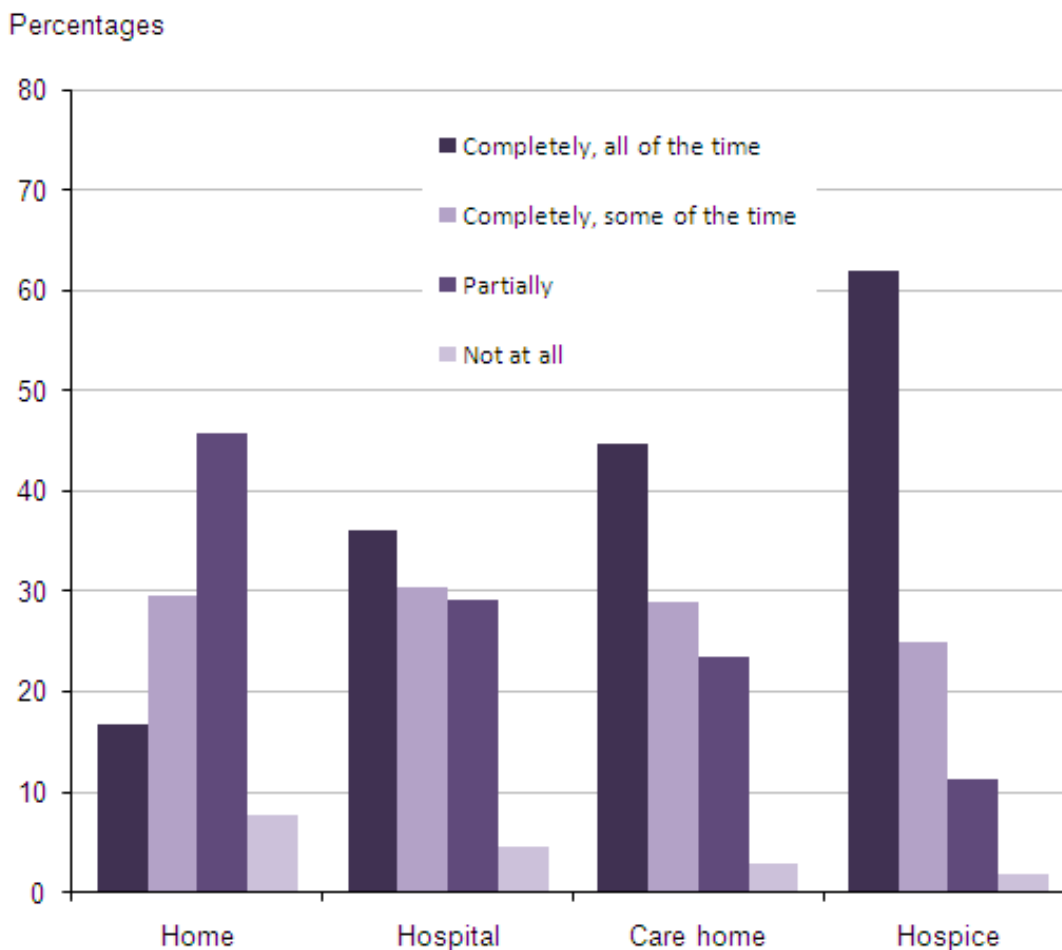
Two questions were asked about coordination of care. One question was asked in relation to those patients who had spent some or all of the last three months at home, about whether community services worked well together. For those who responded to this question, 45 per cent said that the services definitely worked well together and a further 42 per cent said that the services worked well together to some extent.

The second question was asked in relation to those patients who had spent some time in hospital in the last three months and whether hospital services worked well with the GP and other community services. Here, 33 per cent reported these services definitely worked well together and a further 36 per cent said they worked well to some extent. See tables 'Coordination of care'.

Relief of pain and suffering

Questions on relief of pain were relevant only for certain patients. Where it was relevant, relief of pain was reported as being provided 'completely, all of the time' most frequently in hospices (62 per cent) and least frequently among those at home (17 per cent) : see tables 'Relief of pain 3 months' and Relief of pain 2 days.

Figure 3. How well pain was relieved during the last three months of life: by care setting



Source: Office for National Statistics

Download chart

[XLS](#) [XLS format](#)

(17.5 Kb)

Decision making

Two-thirds of respondents (64 per cent) reported that no decisions had been made about care which the patient would not have wanted. However, 17 per cent of respondents said yes to this question.

Respondents reported that the majority of patients (85 per cent) were involved in decisions about their care as much as they wanted. Further details about decision making around care are reported in the tables 'Patients needs & preferences 3 months' and presented by cause of death, place of death and age at death.

Preferences and choice at the end of life

For those who expressed a preference, the majority preferred to die at home (71 per cent). However, the most commonly recorded place of death was a hospital (53 per cent): see tables for 'Preferred priorities'.

Support for relatives, friends or carers at the end of life

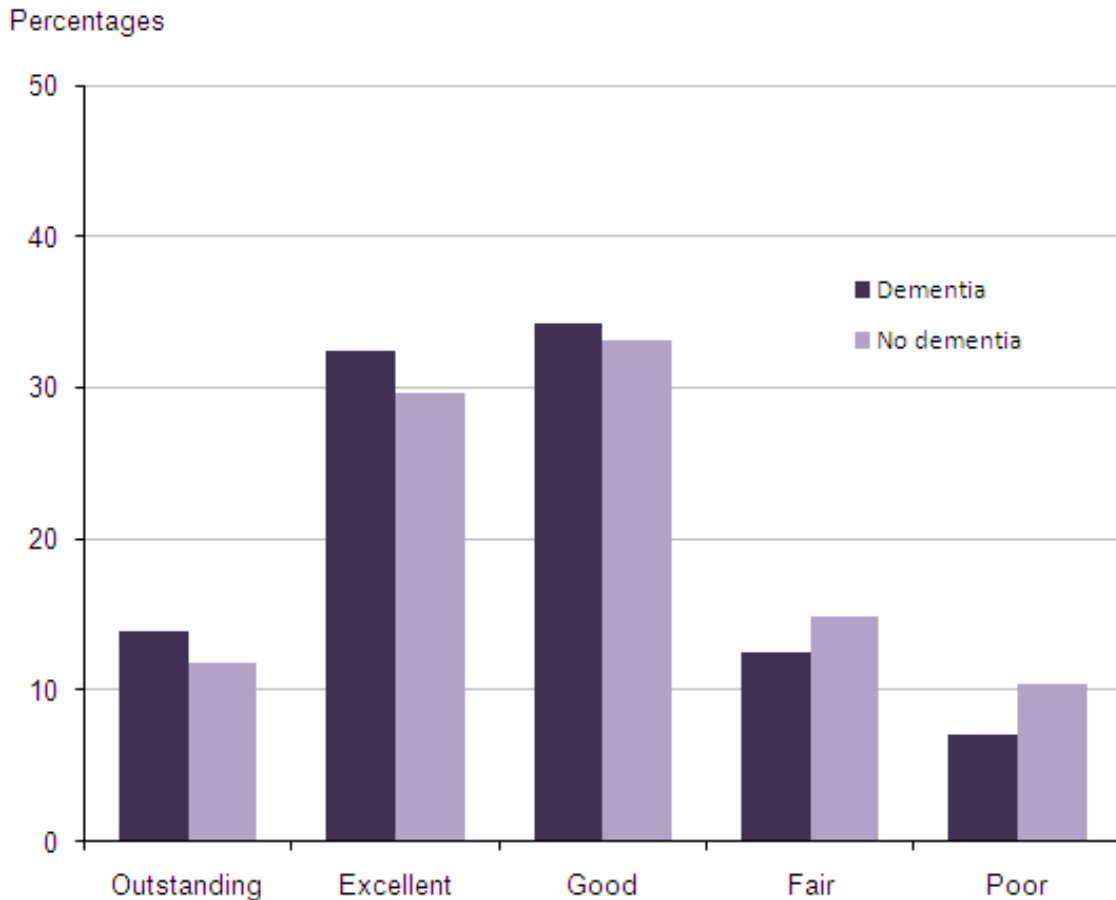
One set of questions asked about the respondent and family of the deceased and the support they received and whether they were dealt with sensitively. More than half of respondents (59 per cent) said that they had definitely been given enough support at the time of the death. A further 27 per cent said that they had to some extent.

When asked whether they had talked to anyone from any support services since the death, most respondents reported that they had not, and did not want to (67 per cent). However, 19 per cent said that they had not, but would have liked to. This was higher for female respondents and younger respondents, under 60 years (21 per cent and 23 per cent respectively): see tables 'Support for carer 3 months' and 'Support for carer 2 days'.

Quality of care for people with dementia

One-fifth of patients had dementia or senility mentioned on their death certificate. This varied across the cause of death groups: 15 per cent of cardiovascular deaths, 4 per cent of cancer deaths and 37 per cent of other deaths had dementia mentioned. More than half of care home deaths had dementia mentioned (56 per cent) and almost one-third of patients aged 80 years or over had dementia mentioned (32 per cent).

Figure 4. Ratings of overall quality of care across all services in the last three months of life: for people with and without dementia mentioned on the death certificate



Source: Office for National Statistics

Download chart

[XLS](#) [XLS format](#)
(17.5 Kb)

Respondents of patients where dementia was mentioned were more likely to rate the overall quality of care as outstanding or excellent (46 per cent) compared with those without (41 per cent), and were less likely to rate the overall quality of care as poor (7 per cent versus 10 per cent): see tables for 'Dementia'.

Sample

The sample for the 2011 VOICES survey was selected from the 306,409 deaths registered between 1st November 2010 and 30th June 2011, which were extracted from the death registration database held by ONS

Informants were contacted between four and 11 months following the death (the recommended time for such surveys).

Sex of deceased

This was determined from information recorded on the death certificate.

- Male (47 per cent of the sample)
- Female (53 per cent of the sample)

Cause of death

All details relevant to the cause of death on the death certificate are coded using the International Statistical Classification of Diseases and Related Health Problems – Tenth Revision, or ICD–10 (WHO, 1992).

Deaths were excluded where the causes of death were accidents, suicides and homicides (ICD–10 codes S000 to Z999) (7,228, 2.4 per cent). The following deaths were included where they were recorded as the underlying cause:

- Cardiovascular Disease (CVD): ICD–10 codes I000 to I999 (31 per cent of the sample)
- Cancer ICD–10 codes C000 to D489 (30 per cent of the sample)
- Other: ICD–10 codes A000 to R999 (excluding CVD and Cancer) (39 per cent of the sample)

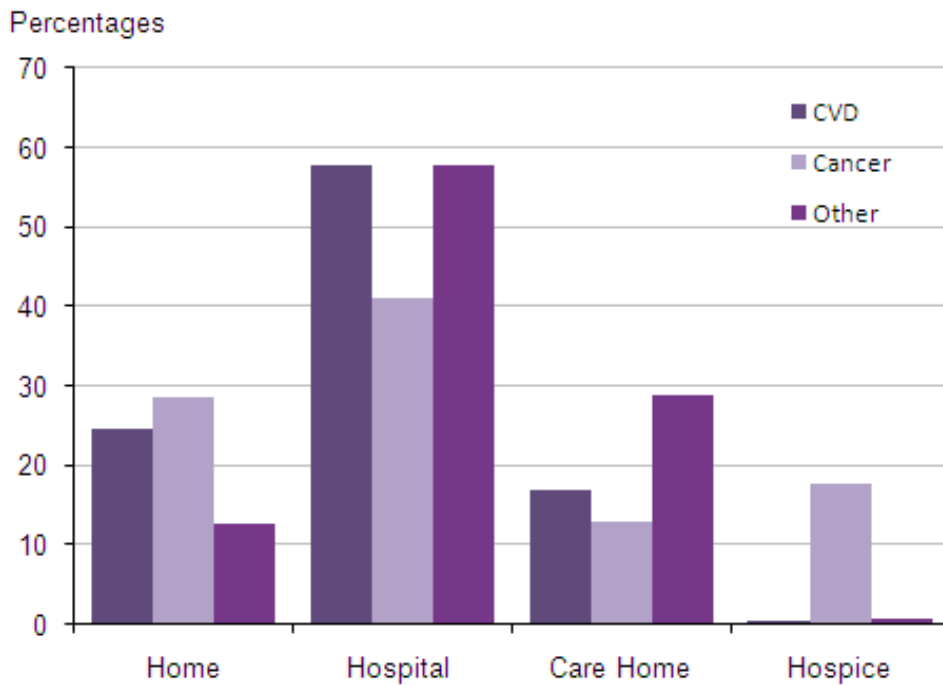
Place of death

Deaths were excluded where the place of death was recorded as 'Elsewhere', which includes external sites (such as roads or parks), public venues (such as shops or restaurants), work places and any other place which could not be identified to a specified location type (3,491, 1.1 per cent). Location types that were included were grouped in the following way:

- Home: the home of the deceased. (21 per cent of the sample)
- Hospital: NHS and private (53 per cent of the sample)
- Care Homes (including residential homes) (20 per cent of the sample)
- Hospices (6 per cent of the sample)

In some cases, it may be appropriate to group residential homes with home, since these all describe the usual residence of the person. However, for the purposes of the 2011 VOICES survey, residential homes were grouped with care homes because the survey addresses the quality of care provided by staff.

Figure 5. Distribution of the sample: by place of death and cause of death



Source: Office for National Statistics

Download chart

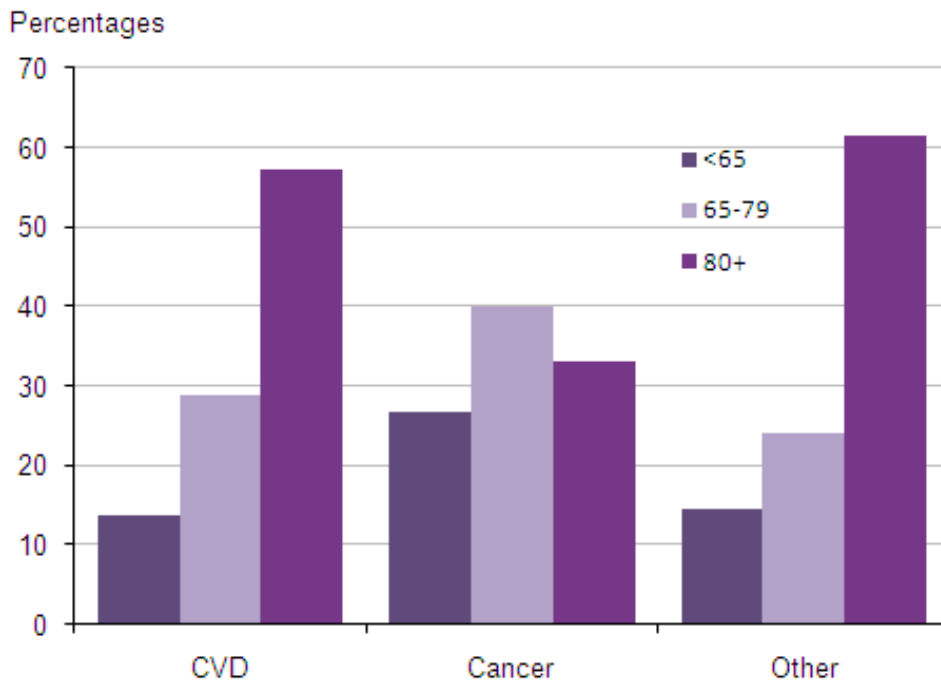
[XLS](#) [XLS format](#)
(26.5 Kb)

Age at death

Deaths of people aged under 18 years were excluded, leaving an age range of 18 to 113 years for this time period. Ages were split into three groups:

- Under 65 years (14 per cent of the sample)
- 65 to 79 years (29 per cent of the sample)
- 80 years or older (57 per cent of the sample)

Figure 6. Distribution of the sample: by place of death and age at death



Source: Office for National Statistics

Download chart

[XLS](#) [XLS format](#)

(17 Kb)

Geographical spread

To ensure a geographical spread, death records were assigned to a PCT cluster based on the postcode of usual residence of the deceased. In 2011, there were 51 PCT Clusters covering the whole of England.

Stratified sample

A further 5,545 (1.8 per cent) of deaths were removed from the sample as the informant name and address fields were blank on the ONS database. These were all deaths that had been referred to a coroner. Of the remaining sample with informant details, 35 per cent were deaths that had been referred to a coroner and the remaining 65 per cent had not. From the 290,145 deaths that were eligible for the survey, a sample of 1 in 6 was drawn (about 49,000) for the actual survey. Sampling methods were implemented to ensure that the sample represented the deaths in England for this period according to sex of the deceased, cause of death, place of death, age and regional spread (based on PCT Clusters).

Response rates

Of the sample of 48,766 deaths, 22,292 completed responses were received from informants, giving a response rate of 45.7 per cent. The overall response rate is comparable to that achieved in a regional postal survey of the bereaved using the same questionnaire (40.0 per cent) (Berkshire and Isle of Wight VOICES pilot survey (Hunt et al, 2011).

The 'Response rates' table shows the response rates by characteristics of the deceased. The ONS mortality database contains the name and address of informants of the death. The relationship of the informant to the deceased is not consistently recorded for all groups. It is not possible to estimate response rates based on respondent details. In the questionnaire, respondents were asked their age, sex, ethnic group and relationship to the deceased. Age and sex of the respondent is reported in the results, but was missing in 10.7 per cent of cases for age and 14.6 per cent of cases for sex.

The VOICES questionnaire

The Views of Informal Carers – Evaluation of Services (VOICES) questionnaire has been developed over many years from face-to-face interview studies and postal surveys undertaken by Professor Julia Addington-Hall (Addington-Hall & McCarthy, 1995; Addington-Hall et al, 1998, Burt et al, 2010). The standard VOICES questionnaire has 144 items and has been used extensively in a number of studies (Fahoury et al, 1996, McPherson & Addington-Hall, 2002). Some surveys have used adapted versions for use with specific populations, such as patients dying from stroke (Young et al, 2008) or chronic obstructive pulmonary disease (Elkington et al, 2005) and cancer patients dying in hospices (Addington-Hall & O'Callaghan, 2009).

The current survey used the VOICES questionnaire short form (VOICES-SF), amended slightly according to recommendations arising from the pilot survey (Hunt et al, 2011). Several questions were further clarified and, for the first time, an additional over-arching question was added. This asked: 'Overall, and taking all services into account, how would you rate his / her care in the last three months of life?'

The layout of the questionnaire was slightly amended to accommodate the needs of a large national survey. Space for respondents to write their own comments was consolidated into one large area at the end of the questionnaire, for separate analysis.

The VOICES-SF questionnaire is personalised using the appropriate pronouns according to the sex of the deceased. All questionnaires were printed in booklet form at ONS using a mail-merge approach to add the details in the letter, the Study ID number on every page and the appropriate gender of the decedent.

Online version of the questionnaire

An online facility was provided for completion of the questionnaire. The VOICES-SF questionnaire is structured so that not all questions are relevant for all respondents, and the online version automatically routed to appropriate questions. There was unlimited space for entry of free text at the end. There was a very low uptake of online completion, with less than 6 per cent of all respondents

using this facility. This is comparable with other postal surveys of the bereaved that have offered an online facility.

Other measures: Index of Multiple Deprivation (2010) for England

This index assesses deprivation across seven domains: Income, Employment, Health Deprivation and Disability, Education, Skills and Training, Barriers to Housing and Services, Crime and Living Environment (Communities and Local Government, 2011). The indices were applied in quintiles at the Lower Super Output Area (LSOA) level using the postcode of the deceased's usual residence. There are 32,482 LSOAs in England, each with a minimum population of 1,000.

Survey administration and methods

All processes related to the administration of this survey were carried out within ONS.

The Survey Process

As is standard in most postal surveys, there were three mail-outs to respondents. The first comprised the mail-merged, personalised questionnaire, a prepaid return envelope, an information leaflet and a reply slip. Copies of the questionnaire and other documents can be found in Appendix B on the Department of Health website.

A reminder letter was sent three weeks after the first mail-out to non-responders only. A final invitation to take part was sent a month after the reminder letter to non-responders, and comprised another questionnaire, a prepaid return envelope, an information leaflet and a reply slip.

The information leaflet was produced in a question and answer format, with contact details of the ONS Survey Enquiry Line team and the postal address of the ONS office in Wales. Letters and the information leaflet gave the Survey Enquiry Line details in large print and stated that large print versions of the questionnaire and leaflet were available. Only a small number were requested and returned. The Information Leaflet encouraged respondents to call the Survey Enquiry Line if English was not their first language but no calls of this nature were received. Some calls were from partially sighted and dyslexic individuals and some completed the questionnaire over the telephone with the ONS Survey Enquiry Line Team member entering the responses using the online facility.

The mailing system, including the prepaid return envelope, was suitable for use abroad and for returning items from abroad. This permitted the inclusion of informants whose usual residence was outside of the UK (about 500).

Data scanning and capture

Completed questionnaires returned to ONS were scanned and processed through a bespoke data capture system, excluding the front page of the questionnaire which contained the name and address of the informant and the name of the deceased. All data were stored under Study ID number only on a secure server with restricted access to those ONS staff working on the survey.

Mechanisms for dealing with distress and complaints

It was recognised that the survey contained questions of a sensitive nature and that respondents were being contacted between four and eleven months following a bereavement (the recommended time for such surveys). Support was provided in a number of ways. A freephone number was provided for the ONS Survey Enquiry Line, which is open outside normal office hours and staffed by highly trained and skilled people. Calls of a particularly sensitive nature or expressing a serious complaint were referred through to the Survey Manager who dealt with them personally. Contact details were also provided for the national charity Cruse Bereavement Care, who provide help and support to those who have lost loved ones.

Sampling and analysis

The selection of a representative sample of approximately 49,000 was undertaken in SAS to ensure representation of all strata and to produce probability sampling weights and stratification values. Non-response weights were created to adjust for bias in response using the same five characteristics: age and sex of the deceased, cause of death, place of death and geographical spread.

Although the sampling method was designed to ensure that the sample represented the deaths in England for this period taking these five factors into account, the sampling stratification was designed for England-level analysis rather than PCT Cluster analysis.

Logistic regressions were run in STATA (version 11) with 'response' as the outcome variable and each characteristic as the predictor. As all five were significant predictors individually, all were entered into the logistic regression and all remained significantly associated with response. The predicted values indicating the probability of response were saved. The response weight was created by taking the inverse of this value. The sampling weight and the non-response weight were combined by taking the product of the two.

Analysis was undertaken in STATA using the survey commands designed to handle complex survey data and to analyse the response using the sample and non-response weights. The most robust use of these commands is to use both the weights and the sampling stratification. Comparisons are made across groups, using the Pearson Chi Square statistic. The computed statistic is adjusted for the survey design, and thus the F statistic is reported, with the significance (p) value.

Uses and users of end of life care statistics

The findings from this survey will be used by a range of users to evaluate the quality of end of life care.

The Department of Health commissioned this survey to follow up on a commitment made in the [End of Life Care Strategy](#). The results of this survey will be used to inform policy decisions and to enable evaluation of the quality of end of life care in different settings, across different ages and different causes of death. Quality of end of life care is also included as an indicator in the [NHS Outcomes Framework](#).

Other key users include the range of organisations and people involved in end of life work. These include the National End of Life Care Network, the National End of Life Care Programme, academics, health researchers and charities, such as Macmillan.

It is anticipated that members of the public, including survey respondents, will have a particular interest in the results of this survey.

Further information

There is a full report on the results of this survey on the [Department of Health website](#): '[First national VOICES survey of bereaved people: key findings report](#)'.

[Appendix A](#) of this report includes a summary of 11 key questions for PCT Clusters. A more detailed report on the survey findings by PCT Clusters will be published in the Autumn 2012.

[Appendix B](#) of the report contains a copy of the VOICES questionnaire used in this survey.

Acknowledgements

The Department of Health, who commissioned this survey, and the Office for National Statistics are grateful to all the respondents who shared their experiences and opinions in the year following their bereavement.

References

Addington–Hall J, McCarthy M. (1995) Regional Study of Care for the Dying: methods and sample characteristics. *Palliative Medicine*, 9: 27–35

Addington-Hall JM, O'Callaghan AC. (2009) A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine*, 23: 190-197

Addington-Hall J, Walker L, Jones, C, Karlsen S, McCarthy M. (1998) A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. *Journal of Epidemiology and Community Health*, 52: 802–807

Burt J, Shipman C, Richardson A, Ream E, Addington-Hall, J. (2010) The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives. *Age and Ageing*, 39: 86–91

Communities and Local Government (2011) The English Indices of Deprivation 2010: Summary, available on the [Communities and Local Government website](#).

Department of Health (2008) End of Life Care Strategy - promoting high quality care for all adults at the end of life. London: HMSO

Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P. (2005) The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine*, 19, 485-491

Fakhoury WKH, McCarthy M, Addington-Hall JM. (1996) Which informal carers are most satisfied with services for dying cancer patients? *European Journal of Public Health*, 6, 181-187

Hunt KJ, Shlomo N, Richardson A, Addington-Hall JM. (2011) VOICES Redesign and Testing to Inform a National End of Life Care Survey. Southampton: University of Southampton.

McPherson CJ, Addington-Hall JM. (2002) How do proxies' perception of patients' pain, anxiety and depression change during the bereavement period? *Journal of Palliative Care*, 20(1), 12-19

World Health Organisation (1992) International Statistical Classification of Diseases and Related Health Problems – 10th Revision. WHO: Geneva, Switzerland.

Young AJ, Rogers A, Addington-Hall JM. (2008) The quality and adequacy of care received at home in the last 3 months of life by people who died following a stroke: a retrospective survey of surviving family and friends using the Views of Informal Carers Evaluation of Services questionnaire. *Health and Social Care in the Community*, 16(4), 419-428.

Background notes

1. The Statistics and Registration Service Act of 2007 authorises ONS to use the data received in connection with death registrations for statistical purposes, including the conducting of surveys. The [Code of Practice for Official Statistics](#) which governs ONS's use of this private information for statistical purposes states clearly how confidentiality will be maintained (Principle 5). The survey plans and materials were reviewed by members of the ONS Ethics Advisory Panel. At all stages of the process procedures were put in place to comply with the Data Protection Act 1998 and the Code of Practice.
2. A list of those given pre-release access to the statistics and written commentary is available on the [ONS website](#). The rules and principles which govern pre-release access are featured within the [Pre-release Access to Official Statistics Order 2008](#).
3. Special extracts and tabulations of data from the National Bereavement Survey (VOICES), 2011, for England are available to order for a charge (subject to legal frameworks, disclosure control, resources and agreement of costs, where appropriate). Such enquiries should be made to:

End of Life Care Team

Health and Life Events Division

Office for National Statistics

Government Buildings

Cardiff Road

Newport

Gwent NP10 8XG

Tel: +44 (0) 1633 456021

E-mail: EOLC@ons.gsi.gov.uk

4. The [ONS charging policy](#) is available on the ONS website.
5. We welcome feedback on the content, format and relevance of this release. The [Health and Life Events user engagement strategy](#) is available to download from the ONS website at. Please send feedback to the postal or e-mail address above.
6. Follow ONS on [Twitter](#) and [Facebook](#)
7. Details of the policy governing the release of new data are available by visiting www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html or from the Media Relations Office email: media.relations@ons.gsi.gov.uk

Copyright

© Crown copyright 2012

You may use or re-use this information (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit www.nationalarchives.gov.uk/doc/open-government-licence/ or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

This document is also available on our website at www.ons.gov.uk.

Statistical contacts

Name	Phone	Department	Email
Julie Messer	+44 (0)1633 456021	End of Life Care Analysis Team	EOLC@ons.gsi.gov.uk

Issuing Body:
Office for National Statistics

Media Contact Details:
Telephone: 0845 604 1858
(8.30am-5.30pm Weekdays)

Emergency out of hours (limited service): 07867 906553

Email:
media.relations@ons.gsi.gov.uk