

Statistical bulletin

# National Survey of Bereaved People (VOICES): 2013

The quality of care delivered in the last 3 months of life for adults who died in England, including variations between different parts of the country and for different groups of patients.

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# 1. Correction

It came to our attention on the 21st of July 2014 that we incorrectly reported a key finding on "preference to die at home". This was corrected on the 22nd of July.

ONS apologises for any inconvenience caused.

## 2. Key findings

- Overall quality of care has not changed significantly between 2011, 2012 and 2013
- Quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home
- For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012
- The dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013
- Pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%)
- Only half of people (50%) who express a preference to die at home, actually die at home

## 3. Background

The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation Of Services) collects information on bereaved peoples' views on the quality of care provided to a friend or relative in the last three months of life, for England. The survey has now been run for three years and was commissioned by the Department of Health in 2011 and 2012, and NHS England in 2013. It is administered by the Office for National Statistics (ONS).

VOICES data provides information to inform policy requirements, including the End of Life Care Strategy, published by the Department of Health in July 2008. This 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](#)).

The 2011 and 2012 survey publications were titled 'National Bereavement Survey'. Following a request from the external steering group for this survey, the name has been changed to 'National Survey of Bereaved People'. This is to clarify that the survey is asked of bereaved people, rather than about bereavement.

This Statistical Bulletin reports on the national results from the 2013 VOICES survey and provides comparisons with findings from the 2011 and 2012 VOICES surveys ([ONS, 2012a](#), and [ONS, 2013a](#)). NHS Area Team findings for the combined results of the 2011 and 2012 surveys can be seen in the bulletin: [National Survey of Bereaved People \(VOICES\) by NHS Area Team \(England\), 2011 – 2012: bereaved peoples' views on care at the end of life](#).

## 4. Guidance on interpreting the results

The VOICES survey is based on a sample and as such is subject to variability in the results found. To aid interpretation, the results are presented with confidence intervals in [reference table 1 \(424 Kb Excel sheet\)](#).

Confidence intervals enable comparisons to be drawn between groups or areas and indicate the amount of uncertainty there is around a figure (the larger the interval, the greater the uncertainty). Where confidence intervals between two figures overlap, we cannot say with certainty that there is more than a chance difference between the figures (see background note 9).

The survey routes respondents to questions relevant to their situation and therefore some questions have more responses than others. For instance, fewer people experienced care in hospices and the number of responses to hospice related questions is far lower than to questions on themes such as support provided to carers at the end of a life, which are relevant to all respondents. Questions with fewer responses are less robust and consequently have wider confidence intervals, reducing the likelihood of significant differences. As well as question response differences, VOICES is also subject to response bias and it is important to remember that the survey reflects the views of responders only and nothing is known about the experiences of people who do not respond. The survey data is weighted to account for probability of selection and response bias (see background note 6). More information on the sample characteristics can be found under the sample section of this report.

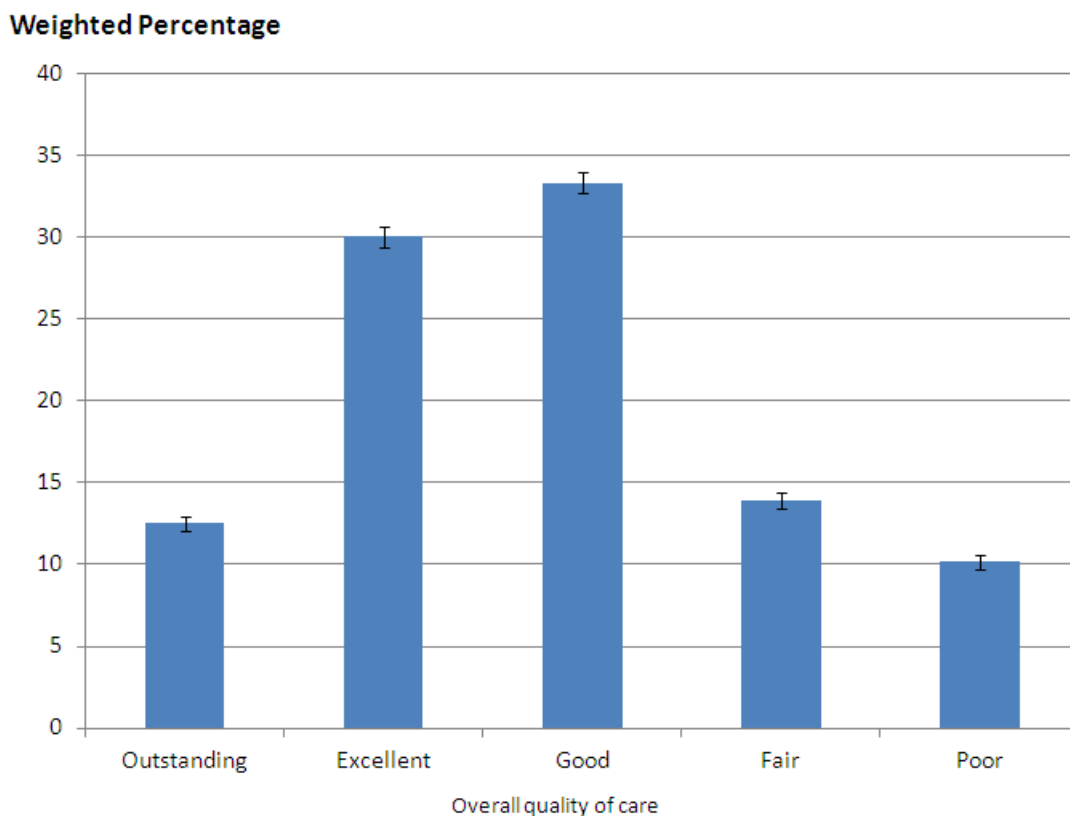
Where figures are quoted from 2011 and 2012, these can be accessed in the two previous annual bulletins (ONS, 2012a, and ONS, 2013a).

## 5. 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 (96%). Of these 13% rated the care as outstanding, 30% as excellent, 33% as good, 14% as fair and 10% as poor (see 'Overall quality of care' table in the reference table 1). Figure 1 presents ratings of overall quality of care across all services in the last three months of life, for 2013.

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

England 2013



As shown in Table 1, there has been no significant change in overall quality of care between 2011 (43%), 2012 (44%) and 2013 (43%). Quality of care rated as outstanding or excellent remains highest for people who died

from cancer (51% rating care as outstanding or excellent each year) and is significantly lower for those who died in hospital than any other location (33% rating care as outstanding or excellent in 2013). Almost half of the sample (48%) died in hospital and half of all deaths in England (ONS, 2013d) occur in hospitals. This indicates the importance of providing high quality care in this setting. While government policy is stressing the need for quality end of life care within hospitals (Department of Health, 2008), the data shows that hospitals are still lagging behind other care settings. An audit of hospital care recommended that specialist palliative care should be more accessible within hospitals and training on care for dying patients should be mandatory for all staff (Royal College of Physicians, 2014).

**Table 1: Overall quality of care rated as outstanding or excellent**

	2013			2012			2011		
	Weighted %	LCL	UCL	Weighted %	LCL	UCL	Weighted %	LCL	UCL
All responses	42.6	41.5	43.6	43.8	42.8	45.0	42.5	41.4	43.6
Cause of death									
Cardiovascular disease	37.7	35.7	39.7	40.1	38.1	42.2	36.9	35.0	39.0
Cancer	50.5	48.4	52.7	50.9	48.9	53.0	50.9	48.8	53.1
Other	40.5	38.9	42.0	40.9	39.3	42.5	39.7	37.9	41.4
Place of death									
Home	53.2	50.5	55.9	53.0	50.4	55.7	53.7	51.0	56.6
Hospital	32.7	31.4	34.1	34.0	32.5	35.4	32.6	31.2	34.1
Care home	50.8	48.7	53.0	52.2	50.0	54.5	51.3	48.8	53.8
Hospice	59.0	54.0	64.1	58.0	53.6	62.8	59.1	54.4	64.1

Source: Office for National Statistics

Notes:

1. Percentages may not sum to 100 due to rounding.
2. Percentages are calculated using sampling and non-response weights.
3. These statistics are based on sample data and are estimates of the population.
4. LCL lower confidence level.
5. UCL Upper confidence level.

Reference table 1 contains results of quality of care ratings within each health care setting. Quality of care remains highest for people who died of cancer when comparing all health care settings. Of respondents who rated care provided by hospices, 77% rated it as excellent. This is significantly higher than for any other health care setting and indicates the importance of specialist palliative care. See [reference table 1 \(424 Kb Excel sheet\)](#) (Quality of care (3mth) tab).

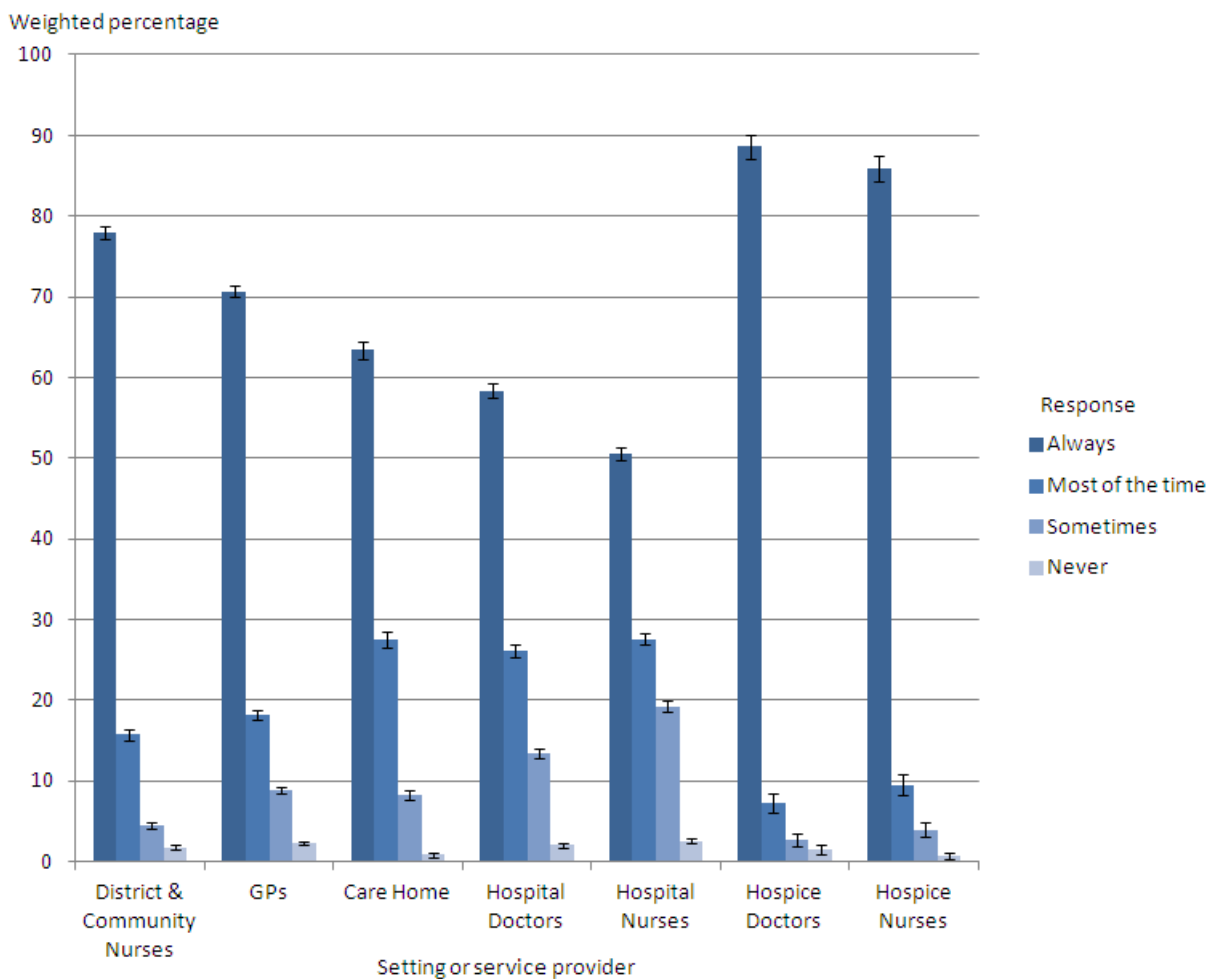
## 6. Dignity and respect

Another aspect of care analysed was whether staff treated the patient with dignity and respect. Staff in hospices received the highest proportion of always showing dignity and respect in the last three months of life (89% for hospice doctors and 86% for hospice nurses). Hospital staff received the lowest proportion always showing dignity and respect (58% for hospital doctors and 51% for hospital nurses). While dignity and respect from nurses is generally reported as lower than from doctors, it has increased significantly for hospital nurses (48% in 2011 to 51% in 2013) and hospice nurses (81% in 2011 to 86% in 2013). Dignity and respect from other professionals has remained unchanged when comparing results from the last three years.

Figure 2 presents information on how often the patient was treated with dignity and respect in the last three months by setting or service provider in 2013.

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

England 2013



Dignity and respect from health care professionals is reported as higher for people who die of cancer, although this is only significant within hospices. Differences in dignity and respect shown to people of different ages tend to be small and non significant. Further details of responses related to dignity and respect reported by: the different care settings and services used in the last three months and the last two days of life, and by cause and age at death are provided (see 'Dignity and Respect 3 months' and 'Dignity and Respect 2 days' tables in [reference table 1 \(424 Kb Excel sheet\)](#)).

## 7. 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, 42% said that the services definitely worked well together, representing a significant fall from 45% in 2012.

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, 31% reported these services definitely worked well together and a further 36% said they worked well to some extent. Statement 8 of the NICE Quality standards for End of Life Care for Adults emphasises the importance of

effectively coordinated care across all relevant settings (NICE, 2011). See 'Coordination of care' table in [reference table 1 \(424 Kb Excel sheet\)](#) .

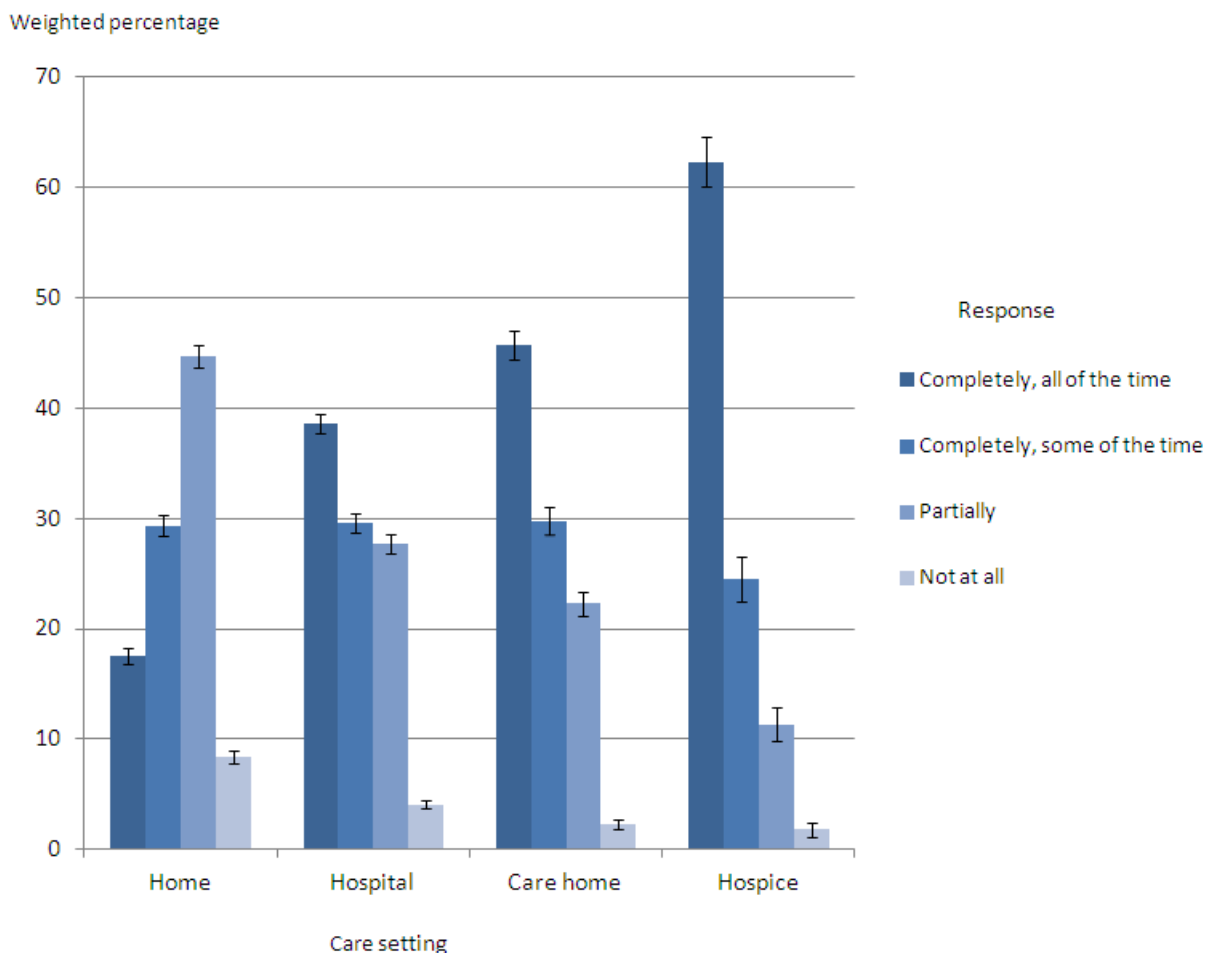
## 8. Relief of pain and suffering

Figure 3 presents results on how well pain was relieved during the last three months of life, by care setting. 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 for patients in hospices (62%) and least frequently for those at home (18%). There have been no significant changes in patterns of pain relief in different settings between 2011 and 2013. Pain relief does not vary significantly between cause of death or age of death in each setting (home, hospital, care home or hospice).

For further information, see 'Relief of pain 3 months' and 'Relief of pain 2 days' tables in [reference table 1 \(424 Kb Excel sheet\)](#).

**Figure 3. How well pain was relieved during the last three months of life: by care setting, England, 2013**

England 2013



## 9. Decision making

Almost two-thirds of respondents (63%) reported that no decisions had been made about care which the patient would not have wanted. However, 17% of respondents said yes to this question. This pattern has remained unchanged since 2011.

Respondents reported that the majority of patients (86%) were involved in decisions about their care as much as they wanted. Statement 3 of the NICE Quality standards for End of Life Care for Adults emphasises the importance of people approaching the end of life feeling satisfied that they have been able to discuss, record and review their needs and preferences and take a role in planning and decision-making, if they would like to do so (NICE, 2011). Further details about decision making around care are reported in the 'Patients needs and Preferences 3 months' tables in [reference table 1 \(424 Kb Excel sheet\)](#), with results presented by cause of death, place of death and age at death.

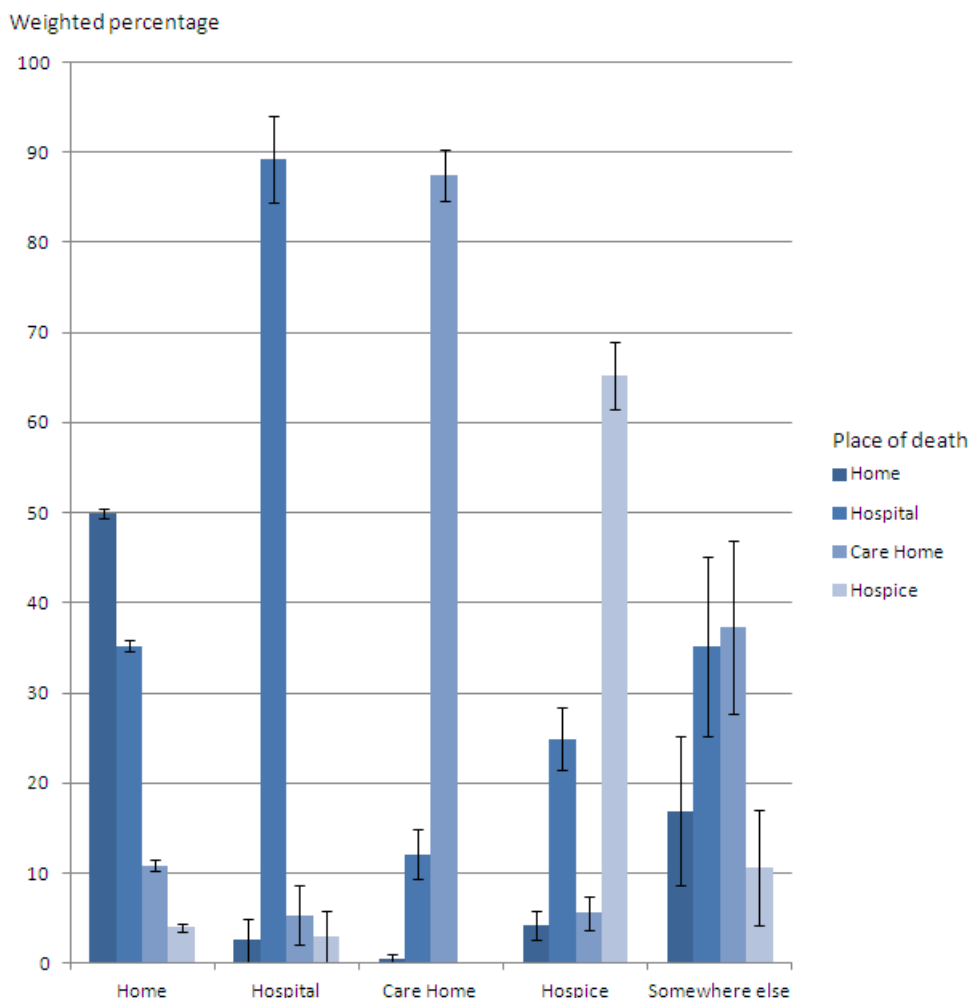
## 10. Preferences and choice at the end of life

Figure 4 presents information on people's preferred place of death and the actual place of death. Only 32% of family members reported that their relative had expressed a preference of where they would like to die and gave further details. For those who expressed a preference, the majority preferred to die at home (79%) while a minority expressed a preference to die in hospital (3%). Previous findings from VOICES demonstrated that 53% of people died in their preferred place of choice, with most people who died at home wanting to die there (99%), and most people who died in hospital also wanting to die at home (85%) (ONS, 2014a).

The majority of people who say where they would like to die express a preference to die at home (79%), but only half (50%) of people who want to die at home actually die there. One third of people (35%) who want to die at home, die in hospital. A quality marker for end of life care is that the individual should be able to die in their place of choice but these statistics demonstrate that this often does not happen (Department of Health, 2009).

**Figure 4. Preferred place of death: by actual place of death, England, 2013**

England 2013





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

One set of questions asked about the support the respondent and family of the deceased received and whether they were dealt with sensitively. More than half of respondents (60%) said that they had definitely been given enough support at the time of the death. A further 26% 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 (68%). However, 18% said that they had not, but would have liked to. This was higher for female respondents (21% versus 14% for males) and younger respondents (23% for under 60 years and 15% for those 60 years and over). There have been no significant changes in these patterns since VOICES was first conducted in 2011.

The NICE Quality standards for End of Life Care for Adults (Statements 7 and 14) focuses on the importance of sensitive communication to those closely affected by death and the need to offer timely support 'appropriate to their needs and preferences' (NICE, 2011). Further information is presented in the 'Support for carer 3 months' and 'Support for carer 2 days' tables in [reference table 1 \(424 Kb Excel sheet\)](#).

## 12. Quality of care for people with dementia contributing to death

Figure 5 presents 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. Doctors are required to record dementia on a death certificate where it contributed to the death, or to the sequence of events leading to a death; it is not recorded in other cases (Dementia mentions are identified if ICD-10 codes F01, F03 and G30 are recorded on the death certificate, see background note 8.) For the whole sample, just 16% of people had dementia or senility mentioned on their death certificate. This varied across the cause of death groups. Where the underlying cause of death was cardiovascular disease, 7% also had a mention of dementia. For cancer deaths, the comparable figure was only 3%, while 30% of other deaths had dementia mentioned. Dementia was mentioned in 42% of care home deaths and almost one-quarter of patients aged 80 years or over (23%).

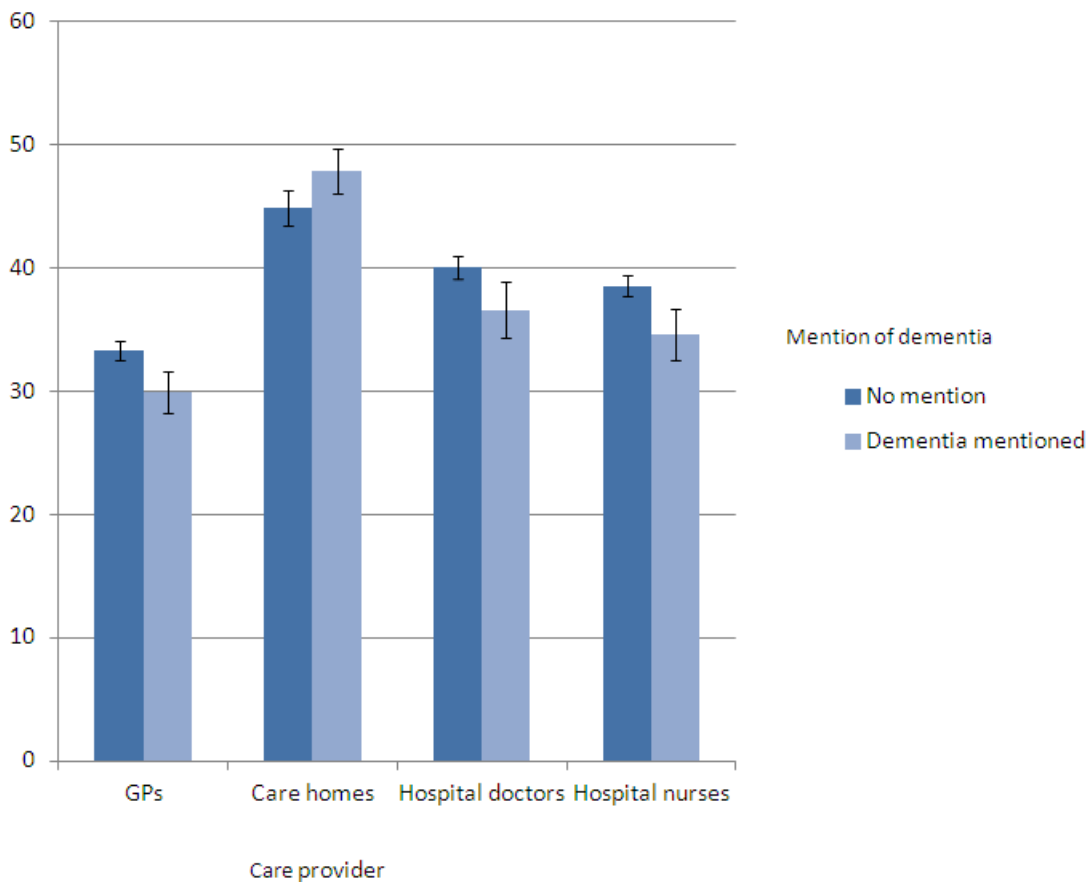
Overall quality of care where dementia was mentioned was rated significantly better than where there was no mention. Care quality was rated as outstanding/excellent in 47% of cases where dementia was mentioned on the death certificate, compared to 42% for no dementia ( See [reference table 1 \(424 Kb Excel sheet\)](#)). While this pattern was consistent in 2011, there were no significant differences between the two groups in 2012.

When comparing excellent quality of care in each setting for people with and without dementia mentioned, excellent care was rated less commonly for people with dementia mentioned on the death certificate. Excellent care was only rated higher for patients with dementia mentioned in care homes (45% no mention compared with 48% where dementia is mentioned), but this difference is not significant. The care of people with dementia mentioned was significantly worse from GPs (33% where dementia is mentioned compared to 30% where dementia is not mentioned) and from hospital nurses (39% where dementia is not mentioned, compared with 35% where dementia is mentioned). However the quality of care from hospital nurses to patients with dementia mentioned has increased significantly when comparing 2011 and 2013 (29% to 35% of cases rated care as excellent).

**Figure 5. Ratings of quality of care across all services in the last three months of life, for people with and without dementia mentioned on the death certificate**

England 2013

Weighted percentage



## 13. Sample

The sample for the 2013 VOICES survey was selected from the 168,719 adult deaths registered between 1st January 2013 and 30th April 2013, which were extracted from the death registration database held by ONS. Records were removed where cause of death and place of death were outside the criteria (see below), where the informant's name and address was missing and where the informant was designated an official (See Background Note 5).

From the 150,111 deaths that were eligible for the survey, a stratified sample of 49,607 was drawn for the actual survey.

Informants were contacted between four and 11 months following the death, the recommended time for such surveys to balance the need for privacy and sensitivity during early bereavement while ensuring reliable recall about care provision (Hunt et al, 2011). The mailing period was also timed to exclude Christmas and the anniversary of the death. The VOICES-SF questionnaire was used: the Views of Informal Carers – Evaluation of Services (VOICES) short-form (see Background Note 4).

## 14. Sex of deceased

This was determined from information recorded on the death certificate.

- Male (44% of the selected sample)
- Female (56% of the selected sample)

## 15. 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 from the sampling frame where the underlying cause of death was accident, suicide or homicide (ICD–10 codes V01 to Y98 and U50.9). The following deaths were included where they were recorded as the underlying cause:

- Cardiovascular Disease (CVD): ICD–10 codes I00 to I99 (29% of the selected sample)
- Cancer ICD–10 codes C00 to D48.9 (This includes benign neoplasms) (27% of the selected sample)
- Other: ICD–10 codes A00 to R99 (excluding CVD and Cancer) (44% of the selected sample)

## 16. Place of death

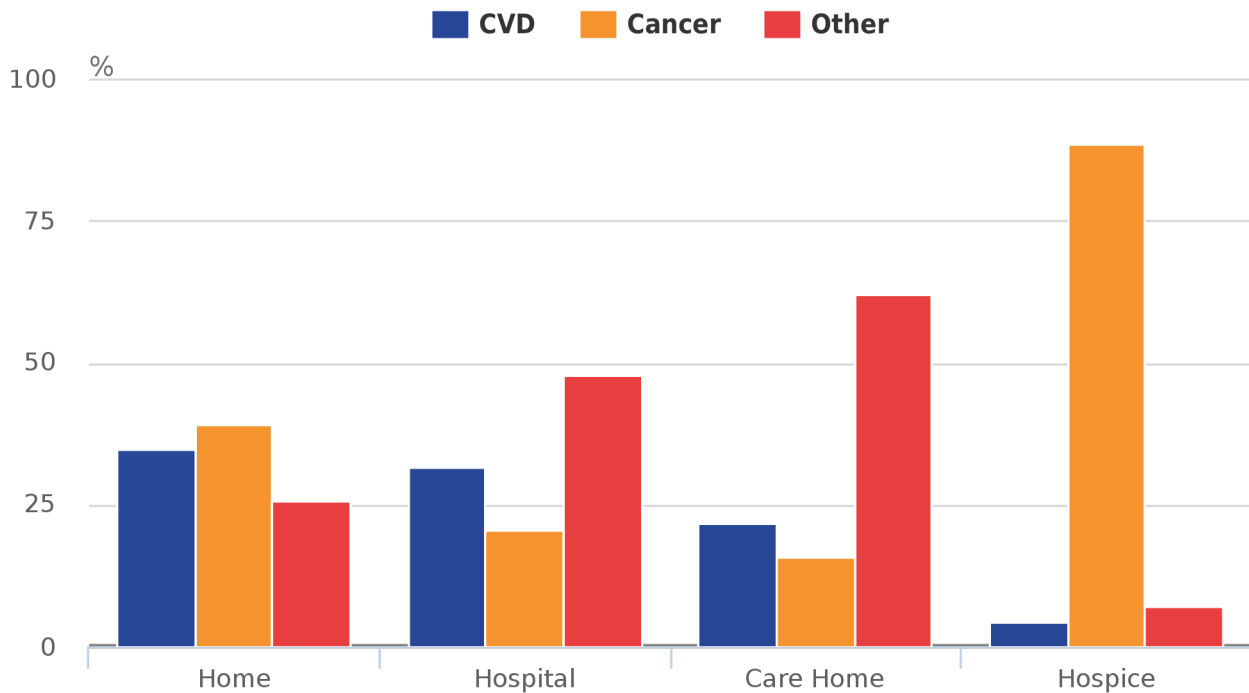
Deaths were excluded where the place of death was recorded as 'Elsewhere', which includes external sites (such as roads or parks), public venues (such as shops or restaurants), work places and any other place which could not be identified to a specified location type. Location types that were included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

- Home: the home of the deceased. (21% of the selected sample)
- Hospital: NHS and private (50% of the selected sample)
- Care Homes (including residential homes) (23% of the selected sample)
- Hospices (5% of the selected 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 2013 VOICES survey, residential homes were grouped with care homes because the survey addresses the quality of care provided by staff. Figure 6 presents the distribution of the sample, by place and cause of death.

**Figure 6. Distribution of the sample: by place of death and cause of death**

England, 2013



Source: National Bereavement Survey (VOICES) - Office for National Statistics

Notes:

1. CVD cardiovascular disease.

## 17. Age at death

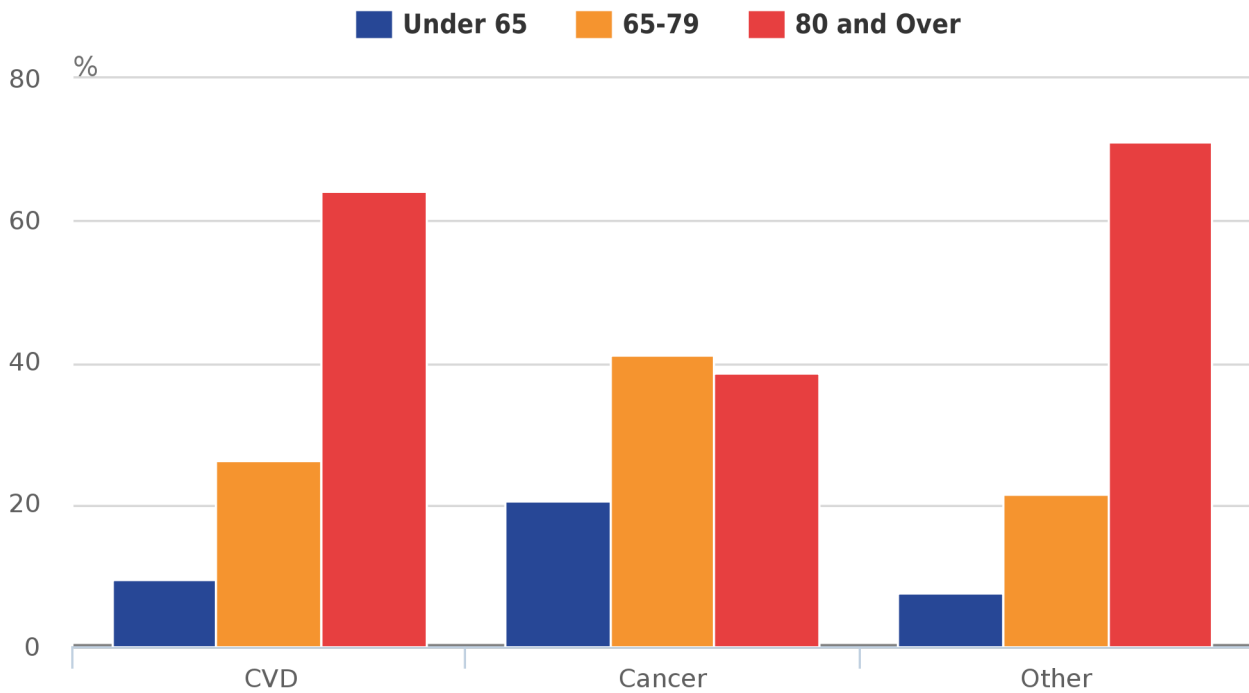
Deaths of people aged under 18 years were excluded, leaving an age range of 18 to 110 years for the sample. Ages were split into three groups:

- Under 65 years (12% of the selected sample)
- 65 to 79 years (28% of the selected sample)
- 80 years or older (60% of the selected sample)

This older age group becomes of greater importance as the number of older adults increases (ONS, 2014b), mortality rates fall (ONS, 2013d) and people live longer (ONS, 2013c).

**Figure 7. Distribution of the sample: by cause of death and age at death**

England, 2013



Source: National Bereavement Survey (VOICES) - Office for National Statistics

Notes:

1. CVD cardiovascular disease.

## 18. Geographical spread

To ensure a geographical spread, death records were assigned to an NHS Area Team based on the postcode of usual residence of the deceased. In 2013, there were 25 NHS Area Teams covering the whole of England.

## 19. Response rates

Of the sample of 49,607 deaths, 22,661 completed responses were received from informants, giving a response rate of 46%. The overall response rate is comparable to that achieved in the previous National VOICES questionnaire ([ONS, 2012a](#), [ONS, 2013a](#)).

The 'Response rates' table presents the response rates by characteristics of the deceased. The ONS mortality database contains the name and address of informants of the death and, in most cases, the relationship of the informant to the deceased. No further information about the informant was available so it was not possible to estimate response rates based on respondent details. Although the questionnaire is sent to the informant on the death certificate, they are encouraged to pass on the questionnaire to another family member if deemed more appropriate. 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 1.2% of cases for age, 5.8% of cases for sex, 2.2% for ethnic group and 1.9% for relationship to the deceased. Of those who stated the relationship, 99% were relatives.

## 20. Survey administration and methods

All processes related to the administration of this survey were carried out within ONS. For details of the Survey Process, Data Scanning and Capture and Mechanisms for dealing with distress and complaints, see the bulletin for the [first National Bereavement Survey \(VOICES\)](#) and the [Quality and Methodology Information](#) paper for this survey.

## 21. 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.

NHS England commissioned this survey to follow up on a commitment made in the Department of Health's [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 one of the key areas in the [NHS Outcomes Framework](#). This has relevance for Domain 2 'Enhancing quality of life for people with long-term conditions' and Domain 4 'Ensuring that people have a positive experience of care'. Indicator 4.6 'Improving the experience of care for people at the end of their lives' uses data from the National Survey of Bereaved People (VOICES) to gather bereaved carers' views on the quality of care in the last three months of life.

Other key users include the range of organisations and people involved in end of life work. These include the National End of Life Care Intelligence Network, the National End of Life Care Programme, academics, health researchers and charities. Service providers and policy makers also use the information to help determine their needs and assess their performance.

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

We welcome feedback from users on the content, format and relevance of this release. Data users can post or email feedback to the address found in the Background Notes section.

## 22. Policy changes and development of the questionnaire

The Liverpool Care Pathway provided a protocol for end of life care which has received criticism in a recent review (NHS England, 2013a). Following this review, the Leadership Alliance for the Care of Dying People was established to deliver improvements in end of life care (NHS England, 2013b). The Leadership Alliance has published a commitment to priorities for improving care of the dying person, including improving communication between staff, the dying person and their carers, involving the dying person and their carers in decisions about their care, and providing an individual plan of care to meet physical and psychological needs of the dying person (Department of Health, 2014).

The VOICES questionnaire is currently being developed to take account of these policy changes. Future surveys will include questions on provision of fluid and nutrition and on the support and communication provided to carers by health care staff. Cognitive testing of these new questions has also led to small changes in existing parts of the questionnaire. These changes will ensure the questionnaire continues to provide policy relevant information and is easy for respondents to complete.

These policy changes will affect the delivery of end of life care, furthering the importance of monitoring quality of care through surveys such as the National Survey of Bereaved People (VOICES).

## 23. Further information

The findings from the [first National Bereavement Survey \(VOICES\)](#), 2011 and the findings [published by PCT Cluster level](#) were published in 2012. A further report examined some of the key [findings by area deprivation \(IMD\)](#) and was published in June 2013. The findings from the 2012 [National Bereavement Survey \(VOICES\)](#) were published in July 2013 and followed by the [National Survey of Bereaved People \(VOICES\) by NHS Area Team](#) in March 2014.

An accompanying report was also published on the Department of Health website “[First national VOICES survey of bereaved people – key findings report](#)” A copy of the VOICES questionnaire used in this survey can be found in web appendix B.

A [Quality and Methodology Information](#) paper for this survey is also available.

The findings from the second and third National Survey of Bereaved People (VOICES) will be reported in February 2015 at NHS Area Team level.

The Department of Health commissioned the first two VOICES surveys carried out in 2011 and 2012 by the Office for National Statistics. From 1st April 2013, responsibility for this area of work was transferred by the Department of Health to NHS England.

The UK Statistics Authority is currently assessing the VOICES survey and associated releases. Further information on the assessment process can be found on the [UKSA webpage](#).

## 24. Acknowledgements

NHS England, 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.

## 25. References

Communities and Local Government (2011). [The English Indices of Deprivation 2010: Summary](#), Available on the Communities and Local Government website at: [www.imd.communities.gov.uk/](http://www.imd.communities.gov.uk/)

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

Department of Health (2009). [End of Life Care Strategy – Quality markers and measures of end of life care](#).

Department of Health (2014). [One Chance to Get it Right: how health and care organisations should care for people in the last days of their life](#).

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.

NHS England (2013a). [‘More Care, Less Pathway’, a review of the Liverpool care pathway](#).

NHS England (2013b). [Leadership Alliance for the Care of Dying People](#). <http://www.england.nhs.uk/ourwork/qual-clin-lead/lac/>

NICE Quality standards (2011). [End of life care for adults: quality standard QS13](#).

Office for National Statistics (2012a). [National Bereavement Survey \(VOICES\), 2011](#) <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/national-bereavement-survey--voices---2011.html>

Office for National Statistics (2012b). [National Bereavement Survey \(VOICES\) by PCT Clusters, 2011](#). <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices--by-pct-clusters/2011/index.html>

Office for National Statistics (2013a) [National Bereavement Survey \(VOICES\), 2012](#) <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2012/stb---national-bereavement-survey-2012.html>

Office for National Statistics (2013b). [National Bereavement Survey \(VOICES\) by Area Deprivation, 2011](#).

Office for National Statistics (2013c). [National Population Projections, 2012–Based Statistical Bulletin](#).

Office for National Statistics (2013d). [Mortality statistics: Deaths registered in England and Wales \(Series DR\), 2012](#).

Office for National Statistics (2014a). [National Survey of Bereaved People – VOICES – by NHS Area Team 2011-2012](#).

Office for National Statistics (2014b). [Estimates of the very old \(including centenarians\) 2002 – 2012, United Kingdom](#).

Royal College of Physicians (2014). [National care of the dying audit for hospitals, England](#).

## 26. Background notes

1. From 2013, the survey name has been changed to ‘National Survey of Bereaved People’, to clarify that the survey is asked of bereaved people, rather than about bereavement. In 2011 and 2012 survey publications were titled ‘National Bereavement Survey’. The change was made as a request from NHS England through the Survey Steering Group.
2. 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 which governs ONS’s use of this private information for statistical purposes states clearly how confidentiality will be maintained (Principle 5). A copy of this can be found on the ONS website at: <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html>. 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 ONS Code of Practice.



3. All processes related to the administration of this survey were carried out within ONS. For details of the Survey Process, Data Scanning and Capture and Mechanisms for dealing with distress and complaints, see the bulletin for the [first National Bereavement Survey \(VOICES\)](#) and the [Quality and Methodology Information paper](#) for this survey.
4. The VOICES questionnaire: The 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 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 deceased. Further details can be found in the bulletin for the [first National Bereavement Survey \(VOICES\)](#) and in the [Quality and Methodology Information paper](#) for this survey.
5. Each year a sample of approximately 49,000 adults in England are selected from the deaths registration database held by ONS. The sampling frame for the 2013 survey included 150,111 people. Deaths were selected from those registered between January 1st and April 30th in 2013. In order to ensure a representative sample of deaths in England and that it covers the key domains of interest, the sample is stratified by cause of death, place of death and NHS Area Team. Respondents are excluded from the sampling frame if the death was due to accident, suicide or homicide or where the death had occurred 'elsewhere' than the designated locations (home, care home, hospital or hospice) or where address details of the informant or deceased were missing. For further details see the [Quality and Methodology Information paper](#) for this survey.
6. Sampling and Analysis: The sample of 49,607 was selected using SAS using a probability proportional to size selection method to ensure representation of all strata. During the selection process, SAS produces sampling weights which account for the probability of selection. Non-response weights were created to adjust for bias caused by differential response. These were produced based the following characteristics: age of the deceased, cause of death, place of death, geographical spread (by NHS Area Team) and level of deprivation. The sampling weight and the non-response weight were combined by taking the product of the two to create the final weight. Analysis was undertaken in SAS using the final weights. Further detail on the methodology can be found in the [Quality and Methodology Information paper](#).
7. 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.
8. Classifications of 'dementia mentioned' are coded by calculating all mentions of ICD-10 codes F01, F03, and G30 which appear anywhere on the death certificate. This classification is presented in this bulletin due to requests for this information, but should be interpreted with caution. ICD guidelines state that Doctors should not write 'dementia' on a death certificate unless it contributed to the sequence of events leading to the death (part 1 of the death certificate) or it contributed to the death (part 2). Therefore mentions of dementia do not reflect actual numbers of people who had dementia, only where it contributed to the death.
9. Confidence intervals provide a measure of the variability, error or uncertainty surrounding a value. They are especially important when using findings from a sample rather than the whole population and are calculated around the estimated value to give a range in which the true value for the population is likely to fall. The width of the confidence interval depends to a large extent on the sample size and so larger studies tend to give more precise estimates of effects (and hence have narrower confidence intervals) than smaller studies. Thus, wide confidence intervals show greater uncertainty and narrow ones show greater confidence in the estimated value. In this bulletin confidence intervals are wider for questions answered by fewer people, such as experiences in hospices, and narrower for questions that all respondents answer.

A confidence interval may be reported for any level of confidence but most commonly is reported at the 95% level. This can be taken to mean that there is only a 5% chance that the true population value lies outside the confidence interval. Confidence intervals are also used to guide interpretation of the data when comparing change over time, examining differences between geographical areas or between certain

groups, such as sex or age. As a general rule and for the same measure, if the confidence interval around one value overlaps with the interval around another, we cannot say with certainty that there is more than a chance difference between the two values. For example, for a value of 45.3 at time 1 with a 95% confidence interval of 42.1 – 48.5 and a value of 47.5 at time 2 with a 95% per cent confidence interval of 44.2 – 50.8, the intervals overlap and so we could not say with certainty that there had been a [significant] change over time. Confidence intervals should therefore be taken into consideration when making comparisons between figures.

10. The annual 2013 deaths registration data is due to be published on the 16th July 2014. Therefore, figures in this bulletin based on deaths registration data, including place of death, cause of death, age and sex of the deceased are provisional. Changes following this release are expected to be minimal; the largest change within a category is for cause of death, where fewer than 30 cases are altered each year. Changes to VOICES data would be smaller than 1% within any category so figures will not be revised.
11. The Voices survey is not subject to regular planned data revisions. In some instances the statistics may be subject to revisions or corrections. Any changes to published statistics adhere to the Office for National Statistics [Revisions and Corrections Policy](#).
12. A list of the names of those given pre-publication access to the statistics and written commentary is available in << **pre-release access – XXXX** >>. The rules and principles which govern pre-release access are featured within the [Pre-release Access to Official Statistics Order 2008](#).
13. Special extracts and tabulations of data from the National Bereavement Survey (VOICES), 2011, 2012 and 2013, 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 Life Events and Population Sources Division Office for National Statistics  
Government Buildings Cardiff Road Newport Gwent NP10 8XG  
  
Tel: +44 (0)1633 456021 Email: [EOLC@ons.gsi.gov.uk](mailto:EOLC@ons.gsi.gov.uk)  
  
The [ONS charging policy](#) is available on the ONS website.
14. 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 [www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/plan-for-mortality-statistics-2012-13.pdf](http://www.ons.gov.uk/ons/guide-method/user-guidance/health-and-life-events/plan-for-mortality-statistics-2012-13.pdf). Please send feedback to the postal or e-mail address above.
15. Follow ONS on [Twitter](#) and [Facebook](#).
16. Details of the policy governing the release of new data are available by visiting [www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html](http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html) or from the Media Relations Office email: [media.relations@ons.gsi.gov.uk](mailto:media.relations@ons.gsi.gov.uk)