National Survey of Bereaved People (VOICES)

User guide 2011-2015

June 2016

A survey carried out for the Department of Health (2011-2012) and NHS England (2013-2015)

National Survey of Bereaved People

VOICES (Views of Informal Carers – Evaluation of Services)

User Guide 2011-2015

Contents

1 Background

The National Survey of Bereaved People (VOICES - Views of Informal Carers - Evaluation of Services) is an annual survey designed to measure the quality of end of life care in the last three months of life. It has been run annually for four years, from 2011 to 2015 and data is available for each year under special license and end user license. Combined datasets for 2011-2012 data and 2012-2013 are also available. This guide is written to provide information on the datasets and how they can be used.

The Department of Health (DH) first commissioned this survey in 2011 to follow up on a commitment made in the End of Life Care Strategy (2008). Previously, very little systematic information was available about the quality of care delivered to people approaching the end of life, despite reports from the Healthcare Commission and the Neuberger review, highlighting deficiencies in care.

The commissioning responsibility for the survey has moved from DH to NHS England, following the restructuring of the Health and Care systems in England in April 2013. In 2015 NHS England ran a consultation for users of the survey where feedback showed that “[VOICES] is a positive move to both recognising and reporting on the things that help and things that don’t work around end of life care” (NHS England, 2015). Users value the data for providing a national context for end of life care, but would benefit if the data was available at lower level geographies than the sampling currently enables.

Each year a sample of approximately 49,000 adults are selected to provide information on the care provided to their friend or family member in the last months of their life. Respondents are selected from those who registered a death within the sampling period and data is collected using the VOICES Short Form (SF) questionnaire. The survey measures aspects of care such as quality of care, dignity and respect, coordination of care and relief of pain. Care is rated across different care settings, including at home, in a hospital, a care home or a hospice. Survey responses are available with information from the deaths registrations database, which includes the deceased’s age at death, sex, cause of death and place of death.

The survey is conducted using robust sampling and weighting methods and has been used to inform official statistics at both the national and sub-national level. This guide is intended to support further use of the data and provide users with summary information on the VOICES survey. More detailed information on the methodology can be found in the Quality and Methodology Information report.

2 The VOICES survey

The VOICES survey uses the VOICES Short Form (SF) questionnaire, which is a modified version of the standard VOICES questionnaire developed by Professor Julia Addington-Hall at Southampton University. The pilot report explains changes that were made to the survey to adapt it for national use (Hunt et al, 2011).

The same version of the survey was used in 2011 to 2013 and questions are worded appropriately to the deceased’s sex, asking about his care, or her care accordingly. In 2014, following criticism of end of life care policies, new questions were developed in relation to provision of fluid, nutrition and other aspects of care at the end of life (Department of Health, 2013). Questions relating to the quality of communication with carers and support for their needs were also added.

The new survey questions were cognitively tested in spring 2014 and included in the 2014 VOICES survey onwards. Cognitive testing of these new questions has also lead to small changes in existing parts of the questionnaire. These changes ensure the questionnaire has continued to provide policy relevant information and is easy for respondents to complete. A full comparison of the old and current VOICES survey is available and the male and female versions of the questionnaires can also be downloaded.

The back page of the VOICES survey invites respondents to write ‘anything you would like to say about the care provided’. This qualitative information is unavailable to external researchers at present.

3 Sampling

Each year a sample of approximately 49,000 adults who died in England is selected from eligible deaths on the deaths registration database held by the Office for National Statistics (ONS). Since 2012, the sample has been selected from deaths occurring from the 1st of January to the 30th of April each year, providing a sampling frame of approximately 150,000 people. In 2011 the sampling period was longer (1st November 2010 to 30th June 2011). This was altered in later years to improve the efficiency of the survey.

Deaths were excluded from the survey sample if they did not meet eligibility criteria. Cases were eligible for inclusion if:

- The death was registered by a friend or relative
- The final underlying cause of death was not caused by accident, suicide or homicide (ICD10 codes V01-Y98 and U50.9)
- The cause of death was cancer (ICD10 codes C000 to D489), cardiovascular disease (ICD10 codes I000 to I999) or other (ICD10 codes A00 to R99 excluding cancer and cardiovascular)
- The deceased was aged 18 or over
- The death occurred in England and the deceased’s usual place of residence was in England
- The death occurred at home, in a hospital, in a care home or hospice
- The person registering a death was a friend or family member
- An address is available for the person registering a death

To ensure the sample represents the deaths in England for the given period and covers the key domains of interest, the sample is stratified according to the cause of death, place of death and geography. For the 2011 and 2012 surveys, geography was based on Primary Care Trust (PCT) clusters. For the 2013 and 2014 surveys this was been based on NHS Area Teams with 25 groups. In 2015 the NHS Area Teams were condensed into 13 groups and this new geography was used in sampling. Each year, the selected sample has been checked to ensure it will provide even representation of sex and age groups.

Table 1: Sampling period and stratification groups by survey year

	2011	**2012**	**2013 - 2014**	**2015**
Sample selection period	All eligible deaths occurring between 1st November 2010 and 30th June 2011	All eligible deaths occurring between 1st January 2012 and 30th April 2012	All eligible deaths occurring between 1st January and 30th April each year	All eligible deaths occurring between 1st January 2015 and 30th April 2015
Cause of death	Cancer Cardiovascular Other causes	Cancer Cardiovascular Other causes	Cancer Cardiovascular Other causes	Cancer Cardiovascular Other causes
Place of death	Home Hospital Care home/Hospice	Home Hospital Care home/Hospice	Home Hospital Care home/Hospice	Home Hospital Care home/Hospice

Geography	PCT Cluster	PCT Cluster	NHS Area Team (2013 geography with 25 areas)	NHS Area Team (2015 geography with 13 areas)

4 Data Collection Methodology

The VOICES questionnaire is sent by post to the person who registered the death of the deceased; this is usually a relative or friend of the deceased. Questionnaires are sent out between 4 and 11 months after the patient has died to avoid the primary grieving period and enable sufficient recall of events. A decline box is provided if a respondent does not wish to participate and questionnaires are returned in a reply paid envelope. As is standard in most postal surveys, if no response is received, this first questionnaire is then followed up with 2 reminders, approximately 4 weeks apart. Respondents are able to pass the questionnaire on to whomever they feel is most suitable to provide the information and can take as much time as they need to complete it.

5 Data processing

Questionnaires are returned to ONS and are scanned and processed through a bespoke data capture system. Cleaning of the data is conducted in SAS and involves: removing duplicate questionnaires where people have sent back more than one questionnaire or reminder, erasing refusals where people have started to complete the questionnaire and withdrawn, removing blank surveys and declines and clearing cases which contain too few responses to provide adequate data. Responses to the VOICES survey are viewed as opinion questions, therefore no cleaning is undertaken to improve continuity of questions. For example, if someone responds that the deceased was not cared for at home and goes on to provide answers questions about care provided at home questions, these responses are all regarded as valid and no changes are made.

6 Response rates

Response rates for each annual survey have been 46% for 2011 to 2013 declining to 43% in 2014 and 2015. The decline can most likely be attributed to changes in the 2014 questionnaire and a general trend of declining response rates in social surveys. The method for declining was made more explicit in 2014 following user feedback during cognitive testing.

Table 2: Sample sizes and response rates by survey year

	2011	2012	2013	2014	2015
Selected sample size	48,776	49,207	49,607	49,614	49,558
Responses	22,292	22,635	22,661	21,403	21,320
Response rate	46%	46%	46%	43%	43%

Further details on the demographics of respondents and non-responders can be found in the annual published data for each survey (See published reports).

7 Weighting

Following data collection, a weight is created for each respondent as the combination of the sampling weight and the non-response weight. The sampling weight is created for each sampled respondent to correct for their unequal probabilities of selection. This weight is the inverse of the probability of selection for each individual case into the sample.

Non response from particular groups can lead to bias in the estimates. VOICES weighting methodology corrects for non response by using logistic regression for age, geography, cause of death, place of death, and sex. If there is significant non-response, then that variable is included in the non-response weighting. In 2014, a review was undertaken of the weighting methodology for Voices and area deprivation was found to have significant non-response; this has been included in the weighting process from 2013 onwards.

The sampling weight and non-response weight are then combined by taking the product of the two.

8 Ethics

The VOICES survey uses the ONS deaths registrations database to draw a sample of eligible deaths for the survey. Section 42 (S42) of the Statistics and Registration Service Act (SRSA) provides ONS with cover to receive the deaths registrations data and to use it for any statistical function. Section 22 (S22) of the SRSA provides cover for ONS to use the data for statistical services to any person inside or outside the United Kingdom and ONS Legal Services have confirmed that this is a lawful use of the data.

Ethical consent for development of VOICES for a national survey was provided by Southampton University Ethics Committee. More recently, the National Statistician's Data Ethics Advisory Committee has been established and reviewed the research protocol for the national VOICES survey. They granted ethical consent for VOICES with minor revisions to the information sheet.

9 Documentation

The following documentation is available:

- VOICES questionnaire: Male and Female versions of the 1st mail out survey are available for each year 2011-2015.
- Information leaflet: The leaflet accompanying each annual survey mail out.
- 2014 Questionnaire changes: This document specifies differences between the 2011-2013 VOICES (SF) questionnaire and the 2014-2015 version.
- Data dictionary: A data dictionary is available for each individual dataset. This lists all available variables with variable name, description, values, routing and details of coding for derived variables.
- The Quality and Methodology Information Report: This provides further details on the methodology for the survey.

10 Datasets and data available

Datasets

A dataset is available for each year that the survey has been run. This includes, 2011, 2012, 2013, 2014 and 2015. In addition, a combined dataset is available for the years 2011-2012 and 2012-2013. These combined datasets were created to provide a larger sample size for analysis at the lower geographical level of NHS Area Team. Published reports and downloadable summary data are available for each year that the survey has been conducted. See the Published Reports section of this guide.

There is no intention to provide a combined 2013-2014 dataset due to changes in the questionnaire between these years. Similarly, a combined publication using 2014-15 data has not been required by NHS England.

Each dataset has a special license (SL) and end user license (EUL) version available. The EUL version contains less detailed variables. For example, only more restricted banded ages of the deceased and respondent are available, place of death by hospice is only available grouped with care homes and ethnicity is not available. The accompanying data dictionary for each year lists in full which variables are available in each dataset. Users should first obtain the EUL version of the data to see if it is sufficient to meet their needs.

Data content

Each dataset has the following information available:

1. Demographics of the deceased taken from the death registrations database. This includes, age, sex, country of birth, cause of death, place of death, date of death
2. Variables attributed to the deceased’s postcode of usual residence including geography and index of multiple deprivation
3. VOICES survey questions
4. Sampling and weighting variables

Each dataset’s accompanying data dictionary lists each variable with details of the variable name, label, values and coding for derived variables. The data dictionaries also outline which variables are available for SL and EUL datasets. Each of these datasets has been risk assessed by ONS Disclosure Control to ensure that identifiable data is only available in a restricted form via special license. EUL datasets do not provide data which may enable individuals to be identified and have fewer restrictions to access them. Users should aim to access the least restricted dataset that meets their needs.

The below table provides a summary of variables that are not available on the EUL dataset with alternative variables listed. These variables have been deemed disclosive and are therefore only available under SL agreements. Both original questions and alternatives coded for the EUL copy are available on the SL dataset. All other variables not listed are on both versions of the datasets.

Table 3: List of variables unavailable on EUL datasets

Variable	**Question**	**Alternative available on EUL**
Age	Age in years of deceased	Agegp (3 age bands as defined from deaths registrations database.) Q59gp (5 age bands as provided by respondents)
DoDdy	Date of death by day	
Dodmt	Date of death by month	
ICD10 codes	Final cause of death and up to 15 mentions, by four digit ICD code	CoD3 (cause of death by cancer, cardiovascular disease and other diseases)
PoD4	Place of death by home, hospital, care home and hospice	PoD3 (place of death by home, hospital and grouped care home/hospice)
Dementia	Deceased had dementia as a final or contributing cause of death	
Q1	How long had he been ill before he died? (7 groups)	Q1gp How long had he been ill before he died (6 groups, with less than 24 hours combined into less than one week)

Q54	Relationship of respondent to deceased (12 groups)	Q54gp Relationship to respondent (3 groups, spouse/partner, son/daughter, other)
Q55	What is your age (respondent) (9 groups)	Q55gp What is your age (5 groups) 18-49, 50-59, 60-69, 70-79, 80+
Q57	Please state which ethnic group you belong to (18 groups)	
Q58	Please state which ethnic group the deceased belonged to (18 groups)	
Q59	What was their age when they died (9 groups)	Q59gp What was their age when they died (5 groups) 18-59, 60-69, 70-79, 80-89, 90+
Q60	What was the deceased's religion (8 groups)	Q60gp What was deceased's religion (2 groups, Christian, no religion/other religion)
Response status	Flag for if the respondent answered the survey.	Only respondents are presented in the data. No information from non responders is available.
IMD_Decile	Index of multiple deprivation, 10 groups	IMD_quintile, 5 groups is available
Strategic clinical networks	Strategic Clinical Networks (13 groups)	NHS Area Team (25 groups)
Technical variables	Selection probabilities, stratification values, selection probabilities, sampling and response weights are not available	Totwgt – the final combined weighting variable is available for weighting to the population of deceased within the sampling period.

It is worth noting that ethnicity of respondents and the deceased is White British for 97% of respondents and deceased. Responses from other ethnicities are inadequate for conducting robust analysis by ethnicity.

11 Using the data

Multicoded questions

Q3 and Q8 are multicoded questions with 15 and 8 possible response options respectively. Each of the possible responses is stored as an individual variable and no cleaning is conducted if for instance, a respondent ticks 'don't know' alongside other options. It is worth noting that respondents tick any response which applies and absence of a response is not equivalent to selecting that, for instance, a service was not provided. Caution should be used in interpreting an absence of a response as a negative.

Missing values

Not applicable, don't know or not sure options are coded as valid responses. For instance Q6 is coded as follows:

During the last three months of his life, while he was at home, how well was his pain relieved?

1 = Does not apply – he did not have any pain

2 = Completely, all of the time

3 = Completely, some of the time

4 = Partially

5 = Not at all

6 = Don’t know

Where no response is received, the question is left blank.

Contradictory responses

No changes to questions are made based on routing questions. For instance, if a person doesn’t state that care was provided in the deceased’s home and goes on to review the quality of services at home, no changes are made. This is due to the questions being opinion based and no knowledge of which responses are correct. Similarly, where questions are left blank by respondents, these are not recoded into missing categories like Don’t know or not applicable.

Analysing by geography

The VOICES survey was initially commissioned to provide national information about the quality of end of life care. Over the years, there has been growing demand for data at subnational levels and this has been feasible at PCT cluster and NHS Area Team level. To provide continuity, NHS Area Team (based on the 2013 categorisation of 25 groups) and Strategic Clinical Networks (13 groups) have been added to the data back series. For 2011 and 2012, this is in place of PCT based geographies. For 2015, the 2015 area team geography was used for sampling, while the 2013 geography is provided with the data for consistency with other years.

The sample size does not support analysis of the data by Clinical Commissioning Group (CCG) or any geography smaller than NHS Area Team. This is the case for both single year data and combined datasets.

Cause of death codes: International Classifications of Diseases (ICD10)

When a death certificate is coded, the final cause of death, with up to 15 contributing causes are recorded. These relate to variables ICD10u (final underlying cause of death) and ICD10_1 to ICD10_15. Each case has a differing number of contributing causes, so not all of the ICD10 variables are populated.

Details for each ICD10 code can be found on the World Health Organisation classifications website.

Cases that are sent to the coroner for a second verdict may be given different final and contributing cause of death codes. On the ONS deaths registrations database these coroner codes are recorded separately to the initial set of ICD codes and the coroner codes supersede the original codes for the purposes of defining cause of death. For the datasets made publicly available, coroner codes have replaced the original cause codes. This is to reduce confusion of having two sets of ‘final cause’ available and reduce the potential for identifying individuals. In 2014, 17 cases had coroner codes assigned.

Weighting and other methodological variables

Strat_n: This represents the number of cases within the stratified category. In 2015 for example, there were 117 different stratified groups (13 area teams x 3 places of death x 3 causes of death = 117). Strat_n represents the number of cases in each of these groups at the time of the sample selection.

SelectionProb: This variable represents the probability of selection of each case. It is calculated by the number in the achieved sample divided by requested sample and adjusted for the size of the strata.

Samplingweight: The sampling weight is the inverse of the selection probability. When applied to calculations, this adjusts for the unequal probability of selection.

NRprob: Logistic regression is used to calculate the probability of non response. This calculates non response likelihood based on place of death (4 groups), cause of death, area team, single year of aged of deceased and (from 2014 onwards) index of multiple deprivation (10 groups).

NRwgt: A non response weight is calculated from response=1 divided by the non response probability.

Totwgt: When weighting these datasets, we recommend weighting by totwgt. This is the total combined weight, which is calculated from the sampling weight and non response weight. This variable will enable production of estimates adjusted for sampling and non response biases.

For further information, see the section on weighting and the accompanying Quality and Methodology Information report.

Totwgt2: This variable can be found on datasets containing more than one year of data and should be used to weight data when analysing the entire dataset. For convenience, Totwgt is also on combined datasets, but should only be used when analysing 1 year of data at a time.

Analysing the data

In 2011 and 2012 Stata was the primary statistical package used in analysing the data. From 2013 SAS has been used. Different statistical packages can result in slightly different results and this can account for small differences between published data and data calculated using different programmes.

12 Notes about particular datasets and variables

Dementia: 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 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.

The broad term of dementia captures a range of brain diseases that decrease the ability to think and remember. As such the definition of dementia using ICD codes can vary. In 2011 and 2012, the definition used in the VOICES publication included ICD10 codes F00-F03, G30 and R54. This was updated in 2013 to include only F01, F03 and G30. For continuity between all available datasets the definition applied in 2013 has been added to all datasets. Therefore published 2011 and 2012 estimates of dementia will not match the variable on this dataset.

2011

COD3: In 2011, the cod3 definition included cases C00 to D99 as cancer. In subsequent years, the definition C00 to D49 has been used. For continuity between years, the cancer category has been amended to C00 to D49 in the available datasets. As a result results based on cod3 will not match published figures: there will be fewer deaths from cancer and more deaths from other causes.

2011 - 2012

Studyid: In 2011 and 2012, the same studyid numbers were used. These remain unchanged in the datasets for individual years, however for the combined 2011-2012 dataset they have been prefixed with the wave of the survey. This ensures unique id numbers are available on each dataset. E.g. the studyid 100001 in 2011 is recorded as **1**100001 on the combined dataset but unchanged in the single year dataset.

2014

Dementia: Due to a problem with 5 ICD10 codes, 5 cases were incorrectly coded as not having dementia. This has been corrected in available data but dementia counts will be slightly higher than in the figures published using the 2014 data.

Q40: ONS detected an error in the questionnaire for Q40 for 2014. Q40 option 4 read 'It was clear that he/she was going to die soon' and should have read 'It was not clear that he/she was going to die soon'. This error made no significant change to the percentage of responders who replied with 'yes', it did however alter the distribution of answers for the remaining options to this question in comparison to other survey years. The error has been corrected and the corrected version of the questionnaire is available to download with the 2014 VOICES bulletin.

13 Published reports (ONS)

The Department of Health commissioned the first 2 VOICES surveys carried out in 2011 and 2012 by the Office for National Statistics. From 1 April 2013, responsibility for this area of work was transferred by the Department of Health to NHS England.

The VOICES survey has now been conducted for 5 years. Available publications are:

- First National Bereavement Survey (VOICES), 2011
- National Bereavement Survey (VOICES) by PCT Cluster level, 2011
- National Bereavement Survey (VOICES) by area deprivation, 2011
- National Bereavement Survey (VOICES), 2012
- National Survey of Bereaved People (VOICES), by NHS Area Team, 2011 to 2012
- National Survey of Bereaved People (VOICES), 2013
- National Survey of Bereaved People (VOICES) by NHS Area Team (England), 2012 to 2013
- National Survey of Bereaved People (VOICES), 2014
- National Survey of Bereaved People (VOICES), 2015

An accompanying report was also published in 2012 on the Department of Health website “First national VOICES survey of bereaved people – key findings report” This contains information about adapting the VOICES survey for national use. A copy of the VOICES questionnaire used in this survey can be found in appendix B.

A Quality and Methodology Information report for this survey is also available. This provides more detailed information about the methodology used in the survey and the strengths and limitations of the survey design.

14 Consultation & future data releases

To ensure the survey remains fit for purpose, NHS England ran a public consultation between 27 March and 23 June 2015. The consultation was open to anyone with an interest in feedback on the quality of end of life care.

A report summarising the feedback from the consultation is available on the NHS England website.

In light of the consultation findings, NHS England has commissioned an options appraisal. This will explore how capturing feedback on End of Life care can be improved by seeking to act upon the consultation responses.

If you would like any further information please contact: englandvoices@nhs.net

15 References

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