Executive summary

The National Bereavement Survey (VOICES - Views of Informal Carers - Evaluation of Services) is an annual survey designed to evaluate the quality of end of life care. 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. Previously, very little systematic information was available about the quality of care delivered to people approaching the end of life, though reports from the Healthcare Commission and others had highlighted 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.

The VOICES survey particularly focuses on the last three months of life. Results are used to inform policy decisions and enable evaluation of the quality of end of life care by sex, in different settings and by different causes of death. Quality of end of life care is also included as an indicator in the NHS Outcomes Framework and the VOICES survey will be used to monitor progress against this.

Each year a sample of approximately 49,000 adults who died in England are selected from the deaths registration database held by the Office for National Statistics (ONS). 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 geographical spread. For 2011 and 2012 surveys, this stratification was based on Primary Care Trust (PCT) clusters. For 2013 survey onwards, this is based on NHS Local Area Team.

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. This 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 four and 11 months after the patient has died. As is standard in most postal surveys this first questionnaire is then followed up with two reminders, if no response is received.

Once fieldwork, data capture, cleaning and processing are complete, findings are disseminated at both the national and sub-national level.

This document contains the following sections:
- Output quality;
- About the output;
- How the output is created;
- Validation and quality assurance;

* Quality and Methodology Information' (QMI) replaced ‘Summary Quality Reports’ (SQR) from 04/11
• Concepts and definitions;
• Other information, relating to quality trade-offs and user needs, and;
• Sources for further information or advice.

Output quality

This document provides a range of information that describes the quality of the output and details any points that should be noted when using the output.

ONS has developed Guidelines for Measuring Statistical Quality; these are based upon the five European Statistical System (ESS) quality dimensions. This document addresses these quality dimensions and other important quality characteristics, which are:
• Relevance;
• Timeliness and punctuality;
• Coherence and comparability;
• Accuracy;
• Output quality trade-offs;
• Assessment of user needs and perceptions; and
• Accessibility and clarity.

More information is provided about these quality dimensions in the sections below.

About the output

Relevance
(The degree to which the statistical outputs meet users’ needs.)

VOICES is an annual survey designed to look at the quality of care in the last three months of life. Each year a sample of approximately 49,000 adults who died in England are selected from the deaths registration database held by the Office for National Statistics (ONS). 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 four and 11 months after the patient has died.

The results from the VOICES survey are utilised by a range of users, including DH and NHS England, to inform policy decisions and to enable evaluation of the quality of end of life care in different settings, across different ages, different causes of death, sex and place of death.

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

Strengths and limitations

The survey design allows comparisons to be made between the quality of care given to people dying at different ages (for example less than 65 years, 65-79 years or 80 years or more) and different causes of death (cardiovascular, cancer or other) and for people receiving care in different settings in the last three months of life (for example home, hospital, care homes and/or hospice).

The number of returned questionnaires is approximately 22,000 (a response rate of around 45%). This number of responses is adequate for analysis at the national level, but limits the robustness of sub-national analysis. For 2011, analysis was published for the 51 Primary Care Trust Clusters. For 2012, sub-national analysis will be published for the 25 NHS Local Area Teams (which replaced PCT clusters in April 2013). 2012 data will be combined with 2011 data, for the purpose of improving the robustness of data. The data do not support extensive analysis at geographic areas smaller than NHS Local Area Teams.

The final section of the VOICES questionnaire provides space for people to write freely about their experiences and views without being restricted to ticking a box. Although this information is not utilised to produce the results for the main annual Statistical Bulletin, it is used to look for recurrent issues reported by respondents as well as strengthening messages in reports on end of life care.
addition, the free text collected from respondents is currently being anonymised so Approved Researchers can apply to analyse this wealth of data.

**Timeliness and punctuality**
(Timeliness refers to the lapse of time between publication and the period to which the data refer. Punctuality refers to the gap between planned and actual publication dates.)

The VOICES Survey is carried out annually with the field period running for approximately 15 weeks. The sample is selected from deaths registered between January and April. Informants are then contacted between four and 11 months following the death (the recommended time for such surveys). Following the data collection period, the data are cleaned, weighted, analysed and tabulated. Reports are created and published three to six months after the end of the field period.

For more details on related releases, the UK National Statistics Publication Hub\(^5\) is available online and provides 12 months’ advance notice of release dates. If there are any changes to the pre-announced release schedule, public attention will be drawn to the change and the reasons for the change will be explained fully at the same time, as set out in the Code of Practice for Official Statistics\(^6\).

**How the output is created**

**Questionnaire development**

The VOICES questionnaire was developed over many years following extensive research asking bereaved relatives about their perceptions of the care given to their deceased relative/friend. The research was carried out by Professor Julia Addington-Hall and colleagues from the University of Southampton.

Following publication of the End of Life Care Strategy\(^1\), Professor Addington-Hall was commissioned by DH to modify the Standard VOICES questionnaire (containing 144 items) in order to measure key aspects of the quality of care identified in the strategy. The pilot study of the short form of the VOICES questionnaire demonstrated the feasibility of the approach and the acceptability of the new survey tool. The findings from the pilot\(^3\) also showed that the questionnaire could detect differences in the quality of care provided in different settings (for example, hospitals versus hospices). Minor modifications were made to the questionnaire following the pilots so that it could be used in the National Bereavement survey. In response to user feedback, an item regarding overall quality of care in the last three months of life was added.

**Sampling**

Each year a sample of approximately 49,000 adults in England are selected from the deaths registration database held by ONS. Deaths are selected from those registered between January and April in 2012 and November 2010 to June 2011 in 2011. 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 geographic spread. 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 were missing.

**Data collection**

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. If the informant feels unable to take part, they are asked to pass the questionnaire on to another family member or friend of the deceased if appropriate.

Informants are contacted between four and 11 months following the death with the data collection period running for approximately 15 weeks. Due to the sensitive nature of the questionnaire, it is necessary to allow respondents adequate time for completion and the opportunity to return to the questionnaire if they do not wish to complete it all in one session.
As is standard in most postal surveys, there is a maximum of three mail-outs to respondents. The first comprises a mail-merged, personalised questionnaire, a pre-paid return envelope, an information leaflet and a reply slip. For the 2012 VOICES survey onwards, the reply slip was removed and a box was added to the back of the questionnaire that respondents could tick if they did not wish to take part. A reminder letter is sent three weeks after the first mail-out to non-responders only, followed by a final invitation to take part a month later, if no response has been returned.

The information leaflet is produced in a question and answer format, with contact details of the ONS Survey Enquiry Line (SEL) team and the postal address of the ONS office in Wales. The information leaflet and letters provide the SEL details in large print and informs respondents that large print versions of the questionnaire and leaflet are available on request. In addition, the information leaflet encourages respondents to call the SEL if English is not their first language. Calls of a particularly sensitive nature or expressing a serious complaint are referred through to the Survey Manager who deals with them personally. Contact details are also provided for the national charity Cruse Bereavement Care, who provide help and support to those who have lost loved ones.

The mailing system, including the pre-paid return envelope, is suitable for use abroad and for returning items from abroad. This permits the inclusion of informants whose usual residence is outside of the UK (about 500 a year).

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

Analysis and 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 weights are constructed as the inverse of the selection probability. The non-response weights are created to adjust for bias in response using the same three characteristics used to stratify the sample: cause of death, place of death (that is, establishment) and regional spread, as well as age and sex of the deceased. These are created through the use of logistic regressions which are run in STATA (version 11) with ‘response’ as the outcome variable and each characteristic as the predictor. Significant predictors are then entered into the logistic regression together to check the association with response. The predicted values indicating the probability of response are saved and the non-response weight is created by taking the inverse of this value. The sampling weight and non-response weight are then combined by taking the product of the two.

Analysis is undertaken in various statistical packages using both the weights and the sampling stratification.

From 2012, sub-national estimates are created using combined data from two consecutive years (for example 2011 and 2012). This increases the robustness of the sub national estimates. For the combined dataset, the weights are adjusted in relation to the sampling frame size for each of the two years.

Disclosure

Statistical disclosure control methodology is applied to the data before publication. This ensures that information attributable to an individual organisation or person is not disclosed in any publication. The Code of Practice for Official Statistics, and specifically Principle 5: Confidentiality, set out practices for how we protect data from being disclosed. The principle includes a guarantee to survey respondents to ‘ensure that official statistics do not reveal the identity of an individual or organisation, or any private information relating to them’. More information can be found in National Statistician’s Guidance: Confidentiality of Official Statistics and also on the ONS Statistical Disclosure Control Methodology page.
Validation and quality assurance

Accuracy
(The degree of closeness between an estimate and the true value.)

The main threats to the accuracy of the data are sampling error and non-sampling error, where non-sampling error includes: coverage error, non-response error, measurement error and processing error.

Sampling error

The VOICES survey is a sample survey, so estimates are subject to sampling variability. Sampling variability is dependent on several factors, including the size of the sample and the effect of weighting on the variable of interest. In order to measure the amount of sampling variability, confidence intervals are calculated around the estimated value, which gives a range in which the true value for the population is likely to fall. For example, with a 95% confidence interval, it is expected that in 95% of the survey samples, the resulting confidence interval will contain the true value that would be obtained by surveying the whole population.

Non-sampling error

The VOICES survey is subject to non-sampling error including non-response. Within non-sampling error there is systematic and random error. Systematic error occurs when data are biased in a certain direction. Random error is the variation in sample data from the true values of the population which occurs by chance. Substantial efforts have been made to avoid errors, for example, the weighting process minimises the effects of non-response bias by accounting for the sampling process.

It is important to note that the sampling and non-response weights are based on the age and sex of the deceased, cause of death, place of death and regional spread, as little is known about the survey respondents.

Coherence and comparability
( Coherence is the degree to which data that are derived from different sources or methods, but refer to the same topic, are similar. Comparability is the degree to which data can be compared over time and domain for example, geographic level.)

The VOICES-SF questionnaire used in the national survey is a modified version of the Standard VOICES questionnaire, developed by Professor Julia Addington-Hall and colleagues from Southampton University, which has been used to assess the quality of care given to patients dying from a range of conditions and in different locations. Studies that have used the Standard VOICES questionnaire may therefore be used to compare data from the national survey.

In order to test the feasibility of the VOICES-SF questionnaire in monitoring the quality of end of life care, the questionnaire was piloted in two PCT clusters, East Berkshire and the Isle of Wight. Results from the pilot study provide some local level data which may be used as a source of comparison with the national survey, although the small sample size may be restrictive.

The VOICES-SF questionnaire used in the national survey is freely available on the DH website. ONS provides support and assistance to other government departments and academics who wish to carry out local studies using the same questionnaire. Results from these local studies may also be used as a source of comparison with the national survey.

As the survey methodology has not changed since the survey commenced, results from each subsequent year will be comparable with previous year’s results. This will allow for the monitoring of progress on improving end of life care both at national and local levels.

Concepts and definitions
(Concepts and definitions describe the legislation governing the output, and a description of the classifications used in the output.)

Underlying cause of death is coded using the International Statistical Classification of Diseases Tenth Revision (ICD-10). ICD-10 replaced the previous revision, ICD-9, in 1995.
End of life refers to the three months prior to the patient’s death.

**Other information**

**Assessment of user needs and perceptions**

(The processes for finding out about uses and users, and their views on the statistical products.)

All Life Events and Population Sources division (LEPS) statistical bulletins seek feedback from users with the inclusion of a standard statement within the background notes. The Health and Life Events User Engagement Strategy is available to download from the ONS website.

LEPS maintains a list of known users, including which statistical outputs they use and the use made of them. All known users will be invited to participate in any future consultation.

Feedback is also received through regular attendance at user group meetings by ONS staff, such as National End of Life Care Intelligence Network meetings, and conferences.

ONS maintained regular contact with DH throughout the development and running of the first two annual surveys. Responsibility for commissioning and overseeing the survey moved to NHS England in April 2013.

A steering group, consisting of representatives from various government departments and end of life care networks, provide feedback and advice on the implementation of the survey as well as the scope and content of the analysis and dissemination of the results.

**Sources for further information or advice**

**Accessibility and clarity**

(Accessibility is the ease with which users are able to access the data, also reflecting the format in which the data are available and the availability of supporting information. Clarity refers to the quality and sufficiency of the release details, illustrations and accompanying advice.)

ONS's recommended format for accessible content is a combination of HTML web pages for narrative, charts and graphs, with data being provided in usable formats such as CSV and Excel. The ONS website also offers users the option to download the narrative in PDF format. In some instances other software may be used, or may be available on request. Available formats for content published on the ONS website but not produced by the ONS, or referenced on the ONS website but stored elsewhere, may vary. For further information please refer to the contact details at the beginning of this document.

For information regarding conditions of access to data, please refer to the links below:

- Terms and conditions (for data on the website)
- Copyright and reuse of published data
- Pre-release access (including conditions of access)
- Accessibility

In addition to this Quality and Methodology Information, Basic Quality Information relevant to each release is available in the relevant Statistical Bulletin.

**Useful links**

VOICES publications along with key estimates are available to download on the ONS website.

The DH website also contains key findings and information including, in Appendix B, a version of the VOICES questionnaire.

The Quality and Methodology Information report can be accessed through Quality Reports for Health and Social Care Statistics on the National Statistics website.

National Bereavement Survey (VOICES) FAQ Page.
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