

Assessment of compliance with the Code of Practice for Official Statistics

Statistics from the National Bereavement Survey

(produced by the Office for National Statistics)

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About the UK Statistics Authority

The UK Statistics Authority is an independent body operating at arm's length from government as a non-ministerial department, directly accountable to Parliament. It was established on 1 April 2008 by the *Statistics and Registration Service Act 2007*.

The Authority's overall objective is to promote and safeguard the production and publication of official statistics that serve the public good. It is also required to promote and safeguard the quality and comprehensiveness of official statistics, and good practice in relation to official statistics.

The Statistics Authority has two main functions:

1. oversight of the Office for National Statistics (ONS) – the executive office of the Authority;
2. independent scrutiny (monitoring and assessment) of all official statistics produced in the UK.

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ASSESSMENT AND DESIGNATION

The *Statistics and Registration Service Act 2007* gives the UK Statistics Authority a statutory power to assess sets of statistics against the *Code of Practice for Official Statistics*. Assessment will determine whether it is appropriate for the statistics to be designated as National Statistics.

Designation as National Statistics means that the statistics comply with the *Code of Practice*. The *Code* is wide-ranging. Designation can be interpreted to mean that the statistics: meet identified user needs; are produced, managed and disseminated to high standards; and are explained well.

Designation as National Statistics should not be interpreted to mean that the statistics are always correct. For example, whilst the *Code* requires statistics to be produced to a level of accuracy that meets users' needs, it also recognises that errors can occur – in which case it requires them to be corrected and publicised.

Assessment reports will not normally comment further on a set of statistics, for example on their validity as social or economic measures. However, reports may point to such questions if the Authority believes that further research would be desirable.

Assessment reports typically provide an overview of any noteworthy features of the methods used to produce the statistics, and will highlight substantial concerns about quality. Assessment reports also describe aspects of the ways in which the producer addresses the 'sound methods and assured quality' principle of the *Code*, but do not themselves constitute a review of the methods used to produce the statistics. However the *Code* requires producers to "seek to achieve continuous improvement in statistical processes by, for example, undertaking regular reviews".

The Authority may grant designation on condition that the producer body takes steps, within a stated timeframe, to fully meet the *Code's* requirements. This is to avoid public confusion and does not reduce the obligation to comply with the *Code*.

The Authority grants designation on the basis of three main sources of information:

- i. factual evidence and assurances by senior statisticians in the producer body;
- ii. the views of users who we contact, or who contact us, and;
- iii. our own review activity.

Should further information come to light subsequently which changes the Authority's analysis, it may withdraw the Assessment report and revise it as necessary.

It is a statutory requirement on the producer body to ensure that it continues to produce the set of statistics designated as National Statistics in compliance with the *Code of Practice*.

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1 Summary of findings

1.1 Introduction

1.1.1 This is one of a series of reports¹ prepared under the provisions of the *Statistics and Registration Service Act 2007*². The Act allows an appropriate authority³ to request an assessment of official statistics against the *Code of Practice for Official Statistics*⁴ in order for them to gain National Statistics status. This report is in response to such a request. The report covers the sets of statistics produced by the Office for National Statistics (ONS) and reported in:

- *National Bereavement Survey (VOICES)*⁵ (*VOICES*)
- *National Survey of Bereaved People (VOICES) by NHS Area Team (England)*⁶ (*VOICES by NHS Area Team*)

1.1.2 Section 3 of this report adopts an ‘exception reporting’ approach – it includes text only to support the Requirements made to strengthen compliance with the *Code* and Suggestions made to improve confidence in the production, management and dissemination of these statistics. This abbreviated style of report reflects the Head of Assessment’s consideration of aspects of risk and materiality⁷. The Assessment team nonetheless assessed compliance with all parts of the *Code of Practice* and has commented on all those in respect of which some remedial action is recommended.

1.1.3 This report was prepared by the Authority’s Assessment team, and approved by the Assessment Committee on behalf of the Board of the Statistics Authority, based on the advice of the Head of Assessment.

1.2 Decision concerning designation as National Statistics

1.2.1 The Statistics Authority judges that ONS does not sufficiently comply with Principle 4, Practices 1 and 2 of the *Code*. This view is based on the finding that insufficient account has been given of the main sources of bias and other error inherent within the survey design (paragraphs 3.3 and 3.4). The Statistics Authority confirms that the statistics published in *VOICES* can be designated as new National Statistics products, subject to ONS implementing the Requirements listed in section 1.5 and reporting them to the Authority by March 2015. The Authority notes that ONS has planned a substantial programme of improvement during 2014 to address the requirements, and that ONS expects

¹ <http://www.statisticsauthority.gov.uk/assessment/assessment-reports/index.html>

² http://www.opsi.gov.uk/Acts/acts2007/pdf/ukpga_20070018_en.pdf

³ Subsection 12(7) of the Act defines ‘appropriate authority’ as Ministers of the Crown, Scottish Ministers, Welsh Ministers, Northern Ireland departments or the National Statistician

⁴ <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/index.html>

⁵ <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2012/stb---national-bereavement-survey-2012.html>

⁶ http://www.ons.gov.uk/ons/dcp171778_355031.pdf

⁷ <http://www.statisticsauthority.gov.uk/assessment/assessment/guidance-about-assessment/criteria-for-deciding-upon-the-format-of-an-assessment-report.pdf>

to report on their implementation in early 2015. After considering ONS's report, the Authority will review the designation of this set of statistics.

- 1.2.2 ONS has informed the Assessment team that it has started to implement the Requirements listed in section 1.5. The Statistics Authority welcomes this.

1.3 Summary of strengths and weaknesses

- 1.3.1 The National Bereavement Survey (NBS) is a new survey under development and ONS is working closely with the commissioners and main users of the survey through the National Survey of the Bereaved Steering Group to identify their needs, develop the questions and improve the granularity of the data provided. Users who contacted us suggested various refinements they would like to see to the outputs. ONS has not yet sought the views of users outside the Steering Group about how well the statistical outputs meet their needs.
- 1.3.2 Users were very appreciative of the national-level statistics provided by the survey and use them in a variety of ways. The majority of users were satisfied with the commentary and they were complimentary about the assistance given by the ONS team in response to queries.
- 1.3.3 ONS does not provide sufficient information about the steps taken to minimise sampling error and non-response bias resulting from the design of the survey. The survey methodology is undergoing internal quality evaluation and the timescale expected for completion of this work is July 2014.
- 1.3.4 ONS told us that an ongoing programme of work to meet the needs of users, including dissemination of non-disclosive data to the UK Data Archive, is being developed, but ONS has not published any details about its plans for this work.

1.4 Detailed recommendations

- 1.4.1 The Assessment team identified some areas where it felt that ONS could strengthen its compliance with the *Code*. Those which the Assessment team considers essential to enable designation as National Statistics are listed in section 1.5. Other suggestions, which would improve the statistics and the service provided to users but which are not formally required for their designation, are listed at annex 1.

1.5 Requirements for designation as National Statistics

Requirement 1	Seek feedback from users regarding the content, presentation and timing of the statistical reports and publish information about users' experiences (para 3.1).
Requirement 2	a) Take steps to investigate the possible sources of bias and error inherent with this survey design, and inform users about the steps taken; and b) publish estimates of the main sources of bias (para 3.2).

- Requirement 3** Provide fuller information about the quality and reliability of the NBS statistics, making clear their strengths and limitations in relation to the range of potential uses (para 3.3).
- Requirement 4** Improve the commentary and analysis in the statistical reports, by explaining technical terms and providing further contextual information, so that it aids user interpretation of the statistics (para 3.4).
- Requirement 5** Publish the data associated with the NBS statistics in an open format that equates to at least a Three Star level under the Five Star Scheme (para 3.6).

2 Subject of the assessment

- 2.1 The National Bereavement Survey (NBS) is an annual survey designed to evaluate the quality of end of life care in England. The statistical report is called *National Bereavement Survey (VOICES)*, VOICES stands for Views of Informal Carers – Evaluation of Services. The Department of Health⁸ (DH) commissioned the pilot of a *VOICES-Short Form* questionnaire which was developed by the University of Southampton. Following the successful pilot, the survey was implemented by ONS as a paper-based questionnaire, which is posted to a sample of approximately 49,000 adults, across England. The questionnaire contains 58 questions and covers care at home, from community nurses, out-of-hours services, GPs, hospitals, hospices, and care received in the last two days in any setting and circumstances surrounding the death.
- 2.2 The sample is drawn from the deaths registration database⁹ administered by ONS. Deaths are selected from those registered between January and April each year and the questionnaire is posted to the person who registered the death of the deceased. The person chosen to receive the questionnaire is contacted between 4 and 11 months following the death.
- 2.3 Completion of the questionnaire is voluntary. The respondent has up to 15 weeks to complete the questionnaire in the privacy of their own home and the forms are returned by pre-paid envelope to ONS. These are anonymised, scanned and the year's data are collated electronically. The data are weighted to take account of the stratified sample design and non-response, and results are presented in data tables and discussed in *VOICES* published by ONS.
- 2.4 Pilot work on the NBS was originally commissioned by DH in 2011 to allow it to meet a commitment made in the *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*¹⁰ published in 2008 to carry out surveys of bereaved relatives. Prior to the NBS being undertaken, very little national information for England was available about the quality of care delivered to people approaching the end of life. A number of organisations highlighted this lack of information as a deficiency, and as a result the NBS was piloted in July 2011. The NBS is used as a measure of progress on improving end of life care both at national and local levels.
- 2.5 DH commissioned and funded ONS £277,077 to run the NBS in 2012 and analyse and publish the results. In April 2013, following the major structural reform of the NHS in England, responsibility for the commissioning of the NBS moved from DH to NHS England¹¹, which has since commissioned the NBS for 2013. Results from the NBS run in 2013 are expected to be published in 2014.
- 2.6 In July 2012, ONS published the first edition of *VOICES*, covering the 2011 survey period, at the national level for England. This was followed by an ad hoc statistical report covering Primary Care Trust (PCT) Clusters¹² in England. ONS

⁸ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215503/dh_128825.pdf

⁹ Information about all deaths registered in England and Wales is held by ONS

¹⁰ <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

¹¹ <http://www.england.nhs.uk/>

¹² <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices--by-pct-clusters/2011/stb-national-bereavement-survey--voices--by-pct-cluster--2011.html>

published supplementary statistics from the NBS by area deprivation using 2011 data on 20 June 2013 and, on 11 July 2013, published the second national-level statistics from the NBS using 2012 data. Subsequently, ONS has merged two years' data and published statistics on 6 March 2014 from the NBS by NHS Local Area Team, which are aggregations of Clinical Commissioning Groups¹³ (CCGs).

- 2.7 The quality of end of life care is one of the key areas in the NHS Outcomes Framework¹⁴. NHS England uses the findings from the NBS to monitor against elements of the Framework. The NBS is used to monitor outcomes in Domain 2 'Enhancing quality of life for people with long-term conditions' and Domain 4 'Ensuring that people have a positive experience of care'. The data from the survey are also used to monitor Indicator 4.6 'Improving the experience of care for people at the end of their lives'. In February 2014, the Authority published a monitoring review about Patient Outcomes Statistics in England¹⁵.
- 2.8 Statistics from the NBS are used by NHS bodies, such as by the NHS Improving Quality Group, NHS Solutions for Public Health Group, as well as regional CCGs and networks, to monitor the quality of care given and to plan future services in their area. Other government users include Public Health England and the Care Quality Commission (CQC), which use the statistics to monitor the quality of care.
- 2.9 Statistics from the survey are used by charities to inform business plans and to lobby the government for improvements in end of life care. Some of the charities known to use the statistics include:
- Marie Curie Cancer Care
 - MacMillan Cancer Support
 - The National Council for Palliative Care
 - Afiya Trust
 - Dying Matters
 - National Hospice
 - The Palliative Care Organisation
- 2.10 The NHS Information Services Division in Scotland publishes *Place of Death from Cancer*¹⁶, National Statistics which describe where deaths from cancer occur in Scotland. ONS publishes *Vital Statistics: Population and Health Reference Tables*¹⁷ for the UK and its constituent countries, National Statistics that cover place of registration and cause of death by age and gender. In 2008, Audit Scotland undertook a study of 5,429 adults to review palliative care

¹³ CCGs are organisations set up by the *Health and Social Care Act 2012* to organise the delivery of health and care services in England and they replace PCTs.

¹⁴ <https://www.gov.uk/government/publications/nhs-outcomes-framework-2012-to-2013>

¹⁵ <http://www.statisticsauthority.gov.uk/assessment/monitoring/monitoring-reviews/monitoring-review-1-2014---official-statistics-on-patient-outcomes-in-england.pdf>

¹⁶ <https://isdscotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2013-04-30/2013-04-30-Place-Of-Death-Summary.pdf?1455324889>

¹⁷ <http://www.ons.gov.uk/ons/rel/vsob1/vital-statistics--population-and-health-reference-tables/index.html>

services in Scotland¹⁸, covering the NHS Greater Glasgow and Clyde, NHS Highland, NHS Borders and NHS Fife geographic areas. A similar survey model to the NBS was used. Similar official statistics for Wales and Northern Ireland are not published; however the Palliative and End of Life Care Priority Setting Partnership¹⁹ is running a survey in both countries to ask the views of patients, families, carers, professionals and charities about the needs for end of life care. The Partnership involves NHS organisations, as well as some of the main voluntary sector organisations involved in palliative care.

- 2.11 The *VOICES* reports are published in HTML format and PDF with supplementary data tables published in Excel format. This equates to a level two rating under the Five Star Scheme proposed in the *Open Data White Paper: Unleashing the Potential*²⁰ and adopted as government policy in November 2012²¹. Five stars represent the highest star rating within the Scheme.

¹⁸ www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care_bereaved_survey.pdf

¹⁹ <http://www.palliativecarepsp.org.uk/>

²⁰ http://data.gov.uk/sites/default/files/Open_data_White_Paper.pdf

²¹ <https://www.gov.uk/government/publications/open-standards-principles/open-standards-principles>

3 Assessment findings

- 3.1 When the contract to run the NBS was awarded to ONS, DH established a formal Steering Group to provide feedback and advice on the implementation of the survey, on the scope and content of the analysis and on the dissemination of the results. The membership is wide ranging and includes representatives from NHS England, DH, CQC, as well as academics from the University of Southampton and third sector organisations such as Marie Curie Cancer Care, Afiya Trust, the National Bereavement Alliance and a service user (a member of the public). The chair of the Steering Group is from NHS England. ONS engages with users in other ways such as participating in the National End of Life Care Intelligence Network, and Health Statistics User Group meetings and conferences. ONS told us that it maintains a list of known users and plans to contact them during future consultations. ONS has documented the use made of the statistics by the NHS and third sector organisations, but has not published this information. It also has not published the views of users about *VOICES*. These are relatively new statistics and it would be helpful for ONS to understand how well the statistical outputs meet the needs of users outside the Steering Group. Users provided the Assessment team with a range of suggestions for ways that they would like the statistics to be presented and enhanced (see annex 3). As part of the designation as National Statistics, ONS should seek feedback from users regarding the content, presentation and timing of the statistical reports and publish information about users' experiences²² (Requirement 1). We suggest that ONS include information about the nature of the use made of the statistics in *VOICES*, referring to the types of use put forward in the Statistics Authority's Monitoring Brief, *The Use Made of Official Statistics*²³.
- 3.2 ONS provides some supporting explanatory material about the survey in the *VOICES* Quality and Methodology Information report²⁴ (QMI) and includes an outline of the sample design in the statistical reports. ONS does not explain how the design of the survey might cause bias and sampling error and how these aspects have been addressed in the analysis of the data. Specifically, more information is required about imputation for item non-response, the effects of seasonality of the sampling (deaths occurring between January and April) and the characteristics of the respondent (generally a relative of the deceased person). The characteristics of the respondent, such as the nature of the relationship with the deceased and the age of the respondent, do have an effect on the reporting of the quality of care, as highlighted by other analyses of the pilot survey²⁵. Pilot work²⁶ published by DH determined the method for weighting the survey data to adjust for non-response; however, this information about the weighting method is not highlighted in *VOICES* or QMI. However, following advice from the Assessment team, ONS provided clear signposting to

²² In relation to Principle 1, Practice 5 of the *Code of Practice*

²³ <http://www.statisticsauthority.gov.uk/assessment/monitoring/monitoring-reviews/monitoring-brief-6-2010---the-use-made-of-official-statistics.pdf>

²⁴ <http://www.ons.gov.uk/ons/guide-method/method-quality/quality/quality-information/health-and-social-care/index.html>

²⁵ Hunt et al; Participant recruitment in sensitive surveys: a comparative trial of 'opt in' versus 'opt out' approaches. *BMC Medical Research Methodology* 2013 **13**:3

²⁶ <https://www.gov.uk/government/publications/voices-redesign-and-testing-to-inform-a-national-end-of-life-care-survey>

the pilot report in its report, *VOICES by NHS Local Area Team* and included a paragraph explaining the weighting method used. At the time of publication, two survey cycles have been completed by ONS and there is now sufficient data to enable more in-depth analyses of bias and error. ONS is itself reviewing the methods used in the survey, but has not published any information about this work. As part of the designation as National Statistics, ONS should a) take steps to investigate the possible sources of bias and error inherent with this survey design and inform users about the steps taken; and b) publish estimates of the main sources of bias²⁷ (Requirement 2).

- 3.3 ONS does not clarify how users should interpret the statistics in light of the sources of error and bias highlighted in paragraph 3.2 above. The commentary in *VOICES* does not make clear whether highlighted differences, such as between care settings or cause of death, are statistically significant and the detailed and summary tables and charts do not make clear the sample sizes upon which the estimates are based. Following advice from the Assessment team, ONS included sample sizes in tables and charts within *VOICES by NHS Local Area Team*. However, ONS does not explain the strengths and limitations of the NBS statistics in relation to the types of uses and decisions that may be informed by them. As part of the designation as National Statistics, ONS should provide fuller information about the quality and reliability of the NBS statistics, making clear their strengths and limitations in relation to the range of potential uses²⁸ (Requirement 3).
- 3.4 *VOICES* does not describe any changes in the statistics over the two years or make clear if comparisons over time are appropriate or not. It uses technical terms and does not explain their meaning, for example, 'not independent of each other', 'weighted' and 'relief of pain 3 months'. *VOICES* mentions the National Institute for Health and Clinical Excellence (NICE) quality standards for end of life care²⁹ and the NHS Outcomes Framework, but the commentary does not explain how the statistics will be used to evaluate end of life care policies. As part of the designation as National Statistics, ONS should improve the commentary and analysis in the statistical reports, by explaining technical terms and providing further contextual information, so that it aids user interpretation of the statistics³⁰ (Requirement 4). We suggest that in meeting this requirement ONS should consider the points detailed in annex 2.
- 3.5 The NBS uses the *VOICES-Short Form* questionnaire developed by the University of Southampton. The QMI highlights the comparability and coherence of the national survey with local surveys, but ONS does not signpost users to similar palliative care statistics published about the other UK countries or make it clear if no equivalent statistics are available. We suggest that ONS advise users about the availability of similar statistics for other parts of the UK and the extent to which equivalent statistics are comparable.
- 3.6 ONS makes the NBS statistics and supplementary tables available as structured data in Excel files but are not available in an open, non-proprietary format which would result in at least a three-star rating under the Five Star Openness Rating Scheme and is seeking to place the survey data in the UK

²⁷ In relation to Principle 4, Practice 2 of the *Code of Practice*

²⁸ In relation to Principle 8, Practice 1 of the *Code of Practice*

²⁹ <http://guidance.nice.org.uk/QS13>

³⁰ In relation to Principle 8, Practice 2 of the *Code of Practice*

Data Archive³¹. As part of the designation as National Statistics, ONS should publish the data associated with the NBS statistics in an open format that equates to at least a Three Star level under the Five Star Scheme³² (Requirement 5).

³² In relation to Principle 8, Practice 4 of the *Code of Practice*

Annex 1: Suggestions for improvement

A1.1 This annex includes some suggestions for improvement to ONS's statistics from the national Bereavement Survey, in the interest of the public good. These are not formally required for designation, but the Assessment team considers that their implementation will improve public confidence in the production, management and dissemination of official statistics.

- | | |
|---------------------|---|
| Suggestion 1 | Include information about the nature of the use made of the statistics in <i>VOICES</i> , referring to the types of use put forward in the Statistics Authority's Monitoring Brief, <i>The Use Made of Official Statistics</i> when documenting use (para 3.1). |
| Suggestion 2 | Publish a plan that outlines the investigations ONS will undertake to better understand the quality issues associated with the survey design (para 3.3). |
| Suggestion 3 | Consider the points detailed in annex 2, in seeking to improve the statistical reports (para 3.4). |
| Suggestion 4 | Advise users about the availability of similar statistics for other parts of the UK and the extent to which equivalent statistics are comparable (para 3.5). |

Annex 2: Compliance with Standards for Statistical Reports

- A2.1 In November 2012, the Statistics Authority issued a statement on *Standards for Statistical Reports*³³. While this is not part of the *Code of Practice for Official Statistics*, the Authority regards it as advice that will promote both understanding and compliance with the *Code*. In relation to the statistical reports associated with *VOICES*, this annex comments on compliance with the statement on standards.
- A2.2 In implementing any Requirements of this report (at paragraph 1.5) which relate to the content of statistical reports, we encourage the producer body to apply the standards as fully as possible.

Include an impartial narrative in plain English that draws out the main messages from the statistics

- A2.3 The first four main points in *VOICES 2012* were appropriate and straightforward to understand, but the last point was unclear and appeared partial. The commentary in *VOICES 2012* did not explain that the statistics are estimates and the uncertainty around the estimates is not well explained. An explanation of the sample size is given little prominence and only appears on page 10 of the report. However, in *VOICES by NHS Area Team*, an explanation of survey estimates, the sample size and the uncertainty around estimates is included.
- A2.4 No glossary is included in either statistical report, but it would have been useful to have had an explanation of the terms such as ‘hospice’ or ‘relief of pain 2 days’ (see paragraph 3.5 for other examples).

Include information about the context and likely uses of the statistics

- A2.5 The commentary in both statistical reports includes a discussion of the user need for the statistics, in the context of DH’s End of Life Care Strategy, the presence of palliative care community services and (NICE) quality standards for end of life care. However, the focus is very much on describing the survey results and little narrative is given about the wider health and care context.

Include information about the strengths and limitations of the statistics in relation to their potential use

- A2.6 ONS does not clarify how users should interpret the statistics in light of the sources of error and bias. The strengths and limitations of the statistics in relation to their potential uses are not discussed in either report, but are briefly mentioned in the QMI linked in the report.

Be professionally sound

- A2.7 ONS does not explain how the design of the survey might have caused bias and sampling error and how these aspects have been addressed in the analysis of the data. Confidence intervals are presented in the Excel data tables, but not in the charts or summary tables in *VOICES*. However, *VOICES by NHS Area Team* includes a description of confidence intervals, visual

³³ <http://www.statisticsauthority.gov.uk/news/standards-for-statistical-reports.html>

representation of these in the charts and an explanation of how to interpret confidence intervals when using the statistics.

Include, or link to, appropriate metadata

- A2.8 The *VOICES* release provides a link to the QMI, but does not include a link to the ONS revisions policy; nor does it make clear whether the statistics are subject to scheduled revisions. However, *VOICES by NHS Area Team* indicates that the statistics are not subject to planned data revisions, includes a link to the ONS revisions policy and highlights the additional method and explanatory information given in the pilot survey report for the NBS.
- A2.9 The publication using data from 2012 is the second year that ONS has published statistics from the NBS, but *VOICES* did not include an indication of whether there had been a change from the statistics published in 2011. Both reports included links to previous NBS statistical reports, released at PCT Cluster and area deprivation level. There was no mention of comparable statistics from other UK nations or internationally.

Annex 3: Summary of assessment process and users' views

A3.1 This assessment was conducted from October 2013 to March 2014.

A3.2 The Assessment team – Penny Babb and Caroline Jones – agreed the scope of and timetable for this assessment with representatives of ONS in October. The Written Evidence for Assessment was provided on 29 November. The Assessment team subsequently met ONS during January to review compliance with the *Code of Practice*, taking account of the written evidence provided and other relevant sources of evidence.

Summary of users contacted, and issues raised

A3.3 Part of the assessment process involves our consideration of the views of users. We approach some known and potential users of the set of statistics, and we invite comments via an open note on the Authority's website. This process is not a statistical survey, but it enables us to gain some insights about the extent to which the statistics meet users' needs and the extent to which users feel that the producers of those statistics engage with them. We are aware that responses from users may not be representative of wider views, and we take account of this in the way that we prepare Assessment reports.

A3.4 The Assessment team received eight responses from the user consultation. The respondents were grouped as follows:

Central government	1
NHS commissioner	3
Voluntary sector	2
Regulator	1
Academic	1

A3.5 Users were very appreciative of the national data provided by the survey and make use of it in a variety of ways. For example, the data are used to brief Ministers, for reviewing the performance of all the sectors providing end of life care, for planning the provision of end of life care and for briefing staff who are assisting bereaved families. Some users were satisfied with the commentary, but others would have preferred more text to accompany the tables. Users were complimentary about the assistance given by the ONS team in response to queries.

A3.6 There were a number of issues that users would like to see addressed in the future, which indicates that the survey and the data are highly valued by those who make use of it. The requests included:

- releasing the statistics in a more timely way
- including data by the new health geographies, for example CCGs
- renaming the survey title to reflect both end of life care and bereavement
- releasing more granular detail about the institutions providing the service, for example hospice or nursing home

- including hyperlinks when referencing files in the commentary
- extending the survey coverage to the other UK countries
- releasing more granular detail about the geography of the institution, for example postcode
- providing research access to the anonymised comments provided by the respondents
- expanding the survey to cover the views of people under 18 years of age
- expanding the survey to include the relatives of deceased young people

Key documents/links provided

Written Evidence for Assessment document

