

**A toolkit for the design and planning of  
locally-led VOICES end of life care surveys**

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## **1. Purpose of the Toolkit**

In 2008 the Department of Health published an End of Life Care Strategy<sup>1</sup> which outlined a series of key areas where changes should be made to the way end of life care is delivered in order to respond to the needs of patients and their families. As a way of monitoring the impact of the Strategy and the way that end of life care is delivered, providers and commissioners are looking to survey end of life care experiences.

This Toolkit sets out practical guidance and information on the design, planning and conduct of an end of life care survey using the VOICES questionnaire. This guidance is based on experience from previous VOICES surveys, and in particular the IMPROVE (Improving Methods and Piloting Recruitment for the VOICES End of life care) Survey which was commissioned by the Department of Health to develop appropriate methods to inform the national VOICES end of life care survey<sup>2</sup>.

## **2. The VOICES (Views of Informal Carers – Evaluation of Services) questionnaire**

VOICES is a postal questionnaire about experiences of end of life care in the last months of life, focusing on quality of care and services received, domains for which patient and proxy agreement are good. The VOICES questionnaire uses the post-bereavement method to gather information from bereaved relatives, friends or carers acting as proxies.

The VOICES questionnaire has been used successfully in at least thirteen surveys with over 4000 respondents<sup>3-6</sup> and further versions have been adapted for, and used successfully in, specific populations such as patients dying from stroke<sup>7</sup>, chronic heart disease, obstructive pulmonary disease (COPD)<sup>8</sup> and dying in a hospice. The standard VOICES questionnaire was extensively re-designed for the IMPROVE Survey<sup>2</sup> to ensure that it meets the needs of the DH End of Life Care Strategy and current practice and policy priorities. The new version, VOICES-Short Form, contains 58 items (in comparison to the previous 144-item version) and covers the following domains:

- Care provided at home
- Urgent care provided out-of-hours
- Care provided by district and community nurses
- Care provided by the GP
- Hospital care
- Hospice care
- Care provided in the last two days of life, across all care settings
- Circumstances surrounding the death (to include Preferred Priorities for Care and

- care for bereaved relatives)
- Demographic factors

VOICES-Short Form (VOICES-SF) has been shown to be a sensitive measure of the experiences of end of life care and can detect differences in the quality of care across care settings and between care providers. VOICES-SF can be used for both research and service evaluation.

It is possible to use all, or just a selection of VOICES sections and this will depend on the aims of the survey. For instance, an acute Trust might be interested to assess the quality of care provided by a particular hospital and so may decide to use the Last Hospital Admission and Circumstances Surrounding the Death sections only.

As is the case for previous versions of VOICES, VOICES-Short Form is gender-specific. Both the male and the female versions are provided in the Appendices.

The following sections of this toolkit outline important considerations for the design and planning of a VOICES survey.

### **3. Aims of the Survey**

An essential step in the planning of a VOICES survey is to develop clear aims and objectives. The methods used to collect the data will vary depending on what the data are to be used for. Most fundamentally, it is important to ascertain whether the survey will be used for research or service evaluation purposes, and to develop a protocol of procedures.

### **4. Ethical approval and ethical practice**

The aims will dictate whether ethical approval should be sought: in the case of service evaluation or redesign, ethical approval may not be necessary. However, if the intention is to conduct a VOICES survey for research purposes, ethical approval is required. The type of approval further depends upon the methods used. For instance, if research data are collected involving NHS data, patients, staff or premises, ethical approval from the National Research Ethics Service (NRES) must be sought. If data collection does not involve NHS data, patients, staff or premises, ethical approval from another appropriate body will suffice (for example a University Research Ethics Committee).

In VOICES surveys without a research focus, ethical practice and standards should be maintained. For instance, by assuring confidentiality to participants, practising informed consent (by providing written information about the survey), establishing mechanisms to deal with distressed responders, as well as responsible systems to manage complaints.

## **5. Identifying the sample**

There are several data sources that can be accessed to identify a sample of deaths, but all have limitations. The choice of method should depend upon the aims of the survey. Potential data sources from which to generate a sample (and their limitations) are set out below.

### **5.1. GP Records**

Accessing a sample through GP records is likely to be the method of choice if the intention is to assess the quality of services across care settings. However, GP records may not account for an entire population within a geographical area and in some areas, there is a high proportion of non-registered persons. It is important to think about the aims of the survey because if the intention is to understand the quality of care for patients registered under a particular GP surgery or GP Consortia, then those not registered within that practice may not need to be part of the survey. A further limitation in using GP registers to identify deaths is that it may be difficult to identify the main carer or individual most suitable to complete the questionnaire. Although it may be possible to identify these individuals at the time of the death, they may be lost to services at the time at which data collection is scheduled.

GP records have the advantage of containing more demographic data than death certificates and would make it possible to over-sample certain groups, such as those from black and minority ethnic groups. It would also be possible to assess occupation and socio-economic status with this type of sampling frame.

### **5.2. Hospital/hospice/care home records**

Hospital records, as GP records, offer the opportunity to gather a considerable amount of demographic data on the population from which the sample will be drawn, thus facilitating over-sampling of certain groups. These types of demographic data also make it possible to assess the degree of non-response bias by comparing responders with non-responders on key variables (discussed in more detail in Section 13.4).

The same disadvantages cited for the use of GP records as a sampling frame exist when using hospital records to identify a sample. For instance, locating the next of kin six months after the death may be an issue. However, unlike in GP records samples where unregistered patients are overlooked, the target population consists of those who were admitted to the hospital/hospice/care home, rather than all living in a geographic area, as would be the case for a survey within a PCT boundary. This ensures a sampling frame that represents all members of the target population.

### **5.3. Death certificates**

This is the method of choice if the aim is to select a complete population within a given geographical area. Using this method it is possible to select all deaths, or sample a proportion of deaths using one of a series of sampling techniques (described in Section 8).

In this model, the informant (the person who registered the death) becomes the participant. However, due to issues of confidentiality, recruitment via death certificates requires the involvement of the Office for National Statistics (ONS), the organisation that manages death certification. This therefore incurs a cost and is calculated per death sampled (between £15-30 per death at the time this Toolkit was published). Via this sampling route, ONS can identify the sample and recruit the informant but completed questionnaires can be returned to those commissioning/managing the survey.

There are limitations to this approach, beyond the added cost incurred. One limitation is that the only point of contact is the informant yet the informant may not have been involved in the care of the person who died. In some cases a death is registered by someone acting in a professional capacity, such as care home staff. In these instances, the informant is not able to provide reliable information on care experiences and quality. A further drawback is that the informant may have changed address since the death was registered and the new address will not be recorded. However, this is a potential problem in most sampling methods and the number of cases where this occurs is likely to be low. For instance in the recent IMPROVE Survey, 1.7% of cases were officially excluded as a result of changed addresses<sup>2</sup>. Of course, the true proportion of wrong addresses is unknown because these figures relied upon the mail provider informing the survey team that the questionnaire was undelivered.

#### **5.4. Self-selection**

A self-selection sample would involve placing posters in GP surgeries, hospitals, Walk-in clinics, community centres and so forth. This method of sampling bypasses some of the problems identified above. For instance, there is no danger of undelivered questionnaires, no problems in tracking the carer/relative five to six months after the death and costs associated with a sampling frame based on death certificates are eliminated.

However, this method is not without its limitations: the most important of these is that it might be more difficult to ensure that those who respond to an advertisement meet the inclusion criteria. For example, ensuring the deceased reside within the boundary of interest (PCT for instance), that respondents contact the survey staff between six to 12 months after the death and the exclusion of suspicious deaths or suicides (details on suggested inclusion and exclusion criteria are covered in Section 7). To ensure that eligibility criteria are met with this sampling technique, it would be necessary to conduct some type of screening of potential participants.

A further limitation with this approach is that it may be difficult to recruit a suitably large sample size, particularly considering that carers/relatives who do not live in the same area as the deceased could not be recruited in this way.



This recruitment method may also affect the reliability of data collected. Unlike with other methods of recruitment based on a defined sampling frame and the presence of demographic and health service related data, self-selection would not guarantee accuracy of certain data. Most notably, cause of death data would be absent and it may also be very difficult to link health services data with the questionnaire data. Questionnaire data may also be subject to self-selection and recall bias with only those who were especially satisfied or dissatisfied responding to the survey. Of course, this risk is present in all recruitment approaches, albeit to a lesser extent.

## **6. Sample size**

To make sense of the findings and to inform planning of future services, it may be appropriate to analyse the data in reference to disease groups and stratify by place of death. However, in order to ensure the necessary statistical power to be able to make such statistical comparisons based on place of death and cause of death, sample size calculations are necessary. Liaison with a statistician is advisable to ascertain the appropriate sample size for a VOICES survey but further guidance can be found in the IMPROVE Survey Final Report<sup>2</sup>.

## **7. Eligibility criteria**

As with all aspects of survey design, the eligibility criteria depend upon the overall aims of the survey. For instance, if the aim is to assess care quality in cancer patients, it will be important to exclude those who died of other causes. However, there are a series of recommended **exclusion criteria** that are relevant to all VOICES surveys:

- Deaths that occurred less than six but more than twelve months before recruitment. This is based on experience from previous VOICES surveys because it balances the need for privacy and sensitivity during early bereavement whilst ensuring reliability of memories about care provision and delivery.
- Deaths in persons younger than 18 years – VOICES has not been validated in younger populations.
- All deaths coded with ICD-10 codes ranging from S000-Z99, thus excluding suspicious deaths, suicides and accidents (ONS are happy to take this approach if recruiting via death certificates). Previous VOICES surveys have excluded Coroner-registered deaths but experience from the IMPROVE Survey has shown that this excludes a large number of deaths that should be included – not just suspicious or accidental deaths. Deaths registered by the Coroner still have an informant's name recorded on the death certificate, thus facilitating recruitment.

## **8. Sampling methods**

There are a series of potential options for sampling methods in a VOICES survey but to some

extent, the choice depends on the chosen method of sample identification. For instance, self-selection would provide a non-probabilistic sample because it would include individuals who nominate themselves to take part, rather than individuals invited to take part according to pre-defined criteria. However, for all other identification methods, a series of sampling methods are available. In the recent IMPROVE Survey, stratified sampling was utilised to ensure that equal proportions of patients who died from particular disease categories and in certain health care settings were recruited. Although this is the method of choice, other methods are also described below:

### **8.1. Stratified sampling**

Stratified sampling may be used to select a sample based on a series of parameters thus ensuring that deaths included in the sample are proportionally representative of all deaths in the defined target population (PCT/hospital/care home). In this approach, deaths are organised according to strata (such as cause of death or age) and can then be randomly selected from each stratum. Unlike in simple random sampling, this method can be used to over-sample certain groups, i.e. disproportional to that group's size in the population. In the IMPROVE Survey, in order to be able to make comparisons based on provider (PCT), age, sex, cause of death and place of death, the following strata were employed:

- PCT
- Sex
- Place of death
  - hospitals (including psychiatric, NHS and non-NHS hospitals)
  - hospices and other communal establishments (including care homes)
  - home (or another home)
- Primary cause of death (using WHO ICD-10 codes)
  - cancer related
  - cardiovascular disease
  - other

The sample frame was then created by sorting deaths according to the variables that define the strata. This approach is better suited to larger samples and can only be used if there is a sample frame providing demographic and service use data – such as all death certificates from a defined period.

### **8.2. Simple random sampling**

This method might be more appropriate if less is known about the target population (and deaths cannot be assigned to strata) or if the intention is to recruit a proportion of the target population without a desire to select based on certain characteristics. In this approach it is again necessary to have a system in place to facilitate random sampling, by using a random number table for instance.

### **8.3. Systematic sampling**

This might be the method of choice if data collection is designed to take place gradually over time, rather than by identifying a sample at the outset. For instance, by recruiting every third death in a PCT over the course of one year.

### **8.4. Cluster sampling**

This might be used if the intention is to recruit participants from two (or more) geographical areas or from different wards in the same hospital. Within each 'cluster', a sample can then be drawn using one of the aforementioned techniques. This method will increase the variability of sample estimates but this limitation may be outweighed by the benefits of being able to increase the number of different populations sampled.

### **8.5. Sampling issues to consider**

Decisions need to be made on whether to identify a sample at the outset and send questionnaires out to all participants at the same time, or whether to recruit gradually over a longer time period. The latter option would allow all respondents to be contacted at the same time after the death: six months afterwards for instance. If a large sample is drawn at one time point, it would be necessary to identify deaths that occurred over a defined time period, as was done in the IMPROVE Survey by applying the 'six to twelve months after death' rule. Some sampling techniques, such as stratified sampling, require that all deaths are identified in advance so that they can be arranged into the strata.

However, the sampling technique may be to recruit all deaths, rather than a proportion - a decision which is probably based on resources. If, for example, the aim is to assess the quality of care for all those who died in a collection of hospital wards over a defined period, then the relatives/carers for all patients who died could be recruited - assuming that they meet the eligibility criteria.

## **9. Survey Management**

There are several important issues to consider when managing a VOICES survey. These include increasing response rates, maintaining ethical practice, giving respondents the opportunity to opt out, and supporting respondents, (the provision of emotional support to bereaved relatives and systems for dealing with complaints will be discussed in the following section). If death certificates are to be used as the sampling frame, then most survey management will be handled by ONS. However, even in this case, survey documentation should be provided and close partnership between ONS and the survey handlers should be maintained.

### **9.1. How to send the questionnaires**

In recent years there has been some debate over the most appropriate and sensitive way to approach potential participants. Ethics Committees have approved different methods with

some recommending that participants are sent the questionnaire in the first instance so they can make an informed decision about participation, and some recommending that this may cause undue distress and that participants should be given the opportunity to request the questionnaire if they wish to take part. In the IMPROVE Survey a trial of these two approaches was conducted in order to investigate their effect on response rate, number of complaints about the survey and number of calls to the bereavement support helpline. The response rate was statistically significantly higher in the group who were sent a copy of the questionnaire in the first instance, and there were no differences in the number of complaints between groups (there were none in either groups) or calls to the bereavement service (one in each group). Therefore, the recommended method of recruitment is to provide potential participants with the questionnaire alongside a letter of invitation.

### **9.2. Giving respondents the option to opt out**

Because of the sensitive nature of the questionnaire and because relatives are not forewarned that they will receive a copy, it is necessary to give invited participants the option to opt out of the survey should they wish. This results in them not being issued with reminder letters unnecessarily. 'Opt out slips' should be sent with the questionnaire and other survey documentation. Once 'opt out slips' are returned, a record should be made to ensure the relative/carer is not contacted again.

A sample 'opt out slip' is available in the appendices and includes space for responders to detail why they do not feel able to take part in the survey. This can provide useful information to help understand the drivers of non-response and can inform the planning of future surveys. A suitable, Freepost envelope should be included with the 'opt out slip', addressed to the survey handling team for processing.

### **9.3. Providing written information about the survey for respondents**

In order to make an informed decision about participation, potential participants must be given sufficient information about the survey. This should include what taking part will involve, why the survey is being carried out and what the findings will be used for. The relative/carer should also be formally invited to take part via an invitation letter. Although both a sample invitation letter and information sheet are provided in the appendices, for clarity and brevity, a detailed, single invitation letter may suffice.

### **9.4. Feedback on the survey findings**

It is becoming increasingly common in surveys to give participants the option of requesting a summary of survey findings. To achieve this, participants will need to provide their address. A sample form is available at the end of the Participant Information Sheet, located in the Appendices.

### **9.5. Additional help in completing the questionnaire**

To increase accessibility, large print versions of the questionnaire and survey documentation could be made available on request. The sample invitation letter therefore has a large print statement directing participants to a phonenumber to request the large print versions.

A facility should also be made available for respondents with questions about the questionnaire itself. This may simply consist of an answerphone where respondents can leave a message for the survey managers.

### **9.6. Reminder letters**

In order to maximise response, carefully timed reminder letters are a useful tool. Experience from previous VOICES surveys suggests that two reminders are optimum and are associated with a considerable increase in response thereafter. The most appropriate timing of these reminders is three weeks after the initial mail-out, and then again three weeks later. The management of reminder letters may be more complex if deaths are selected prospectively, rather than as a complete sample at one time point. In this case, a database could be constructed to flag up timing of reminder letters. A sample reminder is available in the appendices.

### **9.7. Online methods**

Online methods are increasingly being used in surveys and their use should be considered in a VOICES survey. Aside from increasing choice for participants, online methods may help to increase response. In the IMPROVE Survey, 9.8% completed online.

In order to ensure that all those who take part are invited to do so (or in the case of self-selection surveys, to ensure that all participants meet the eligibility criteria), it is necessary to provide participants with a password to gain access to an online version. This password should be included in the survey documentation, alongside instructions on how to complete online.

Several online survey software packages are available, some with no charge, but the chosen package must include a password facility to control access. Most survey packages will automatically save the completed questionnaire to a location that can be accessed by those handling the survey. Unlike with paper versions of the questionnaire, in online surveys, data are available on all those who start the questionnaire, rather than only those who return a paper copy.

## **10. Mechanisms for dealing with distress**

Given the sensitive nature of VOICES surveys and the vulnerability of informants, a series of support structures should be put in place. They should be designed to achieve the following:

- Provide emotional support
- Facilitate the reporting of complaints
  - About the care provided
  - About the survey

### **10.1. Responding to emotional distress**

A VOICES survey has the potential to provoke distress and raise issues that a respondent might need help to explore. Therefore, a mechanism should be in place to manage this eventuality. In the IMPROVE Survey, collaboration with Cruse Bereavement Care was instrumental in this and in local surveys it might be appropriate to approach local bereavement counselling services to offer this type of support (such as a hospice/hospital-led service). Cruse contributed to the development of the participant documentation in the IMPROVE Survey thus ensuring that the wording of the questionnaire and information sheet were appropriate. These have been modified for locally-led surveys and are available in the appendices.

Ideally, the counselling service would be able to provide both telephone support (via a telephone line) and face-to-face support if necessary. The telephone number should be provided on all survey documentation, as should details of opening times, and whether there is an answerphone service. Although experience in these types of surveys suggests that demand for this support is limited, provision of emotional support in response to participant needs is essential.

In the case of non-English speakers, a further helpline or service can be made available. This should be arranged through discussions with local services who work with minority populations.

### **10.3. Responding to complaints**

A framework for dealing with complaints about the conduct of the survey or the care received by the decedent should be established.

#### **Complaints about the end of life care provided**

Where negative comments are detailed on the questionnaire, no direct action should be taken unless the participant explicitly requests that this should be the case and provides their contact details. However, complaints expressed verbally or in writing must be taken seriously and should be passed on to the organisation responsible for handling such complaints: such as the Patient Advice and Liaison Service (PALS). All complaints procedures should align with the recently published New Health Care System Architecture for Complaints. The use of a direct telephone line for this purpose should be explored.

### **Complaints about the survey**

The information sheet should direct all respondents to an independent nominated person who is not a member of the survey team - to a service administrator, for example.

## **11. Promoting the survey**

Increasing response rates and reducing response bias is desirable in population surveys. Aside from the use of reminder letters, there are various methods of increasing response rates but some are more suited to certain types of survey design. In the IMPROVE Survey, several approaches were used but the most successful was the use of press releases with local media organisations. Suggested approaches are detailed below:

### **11.1. Press releases**

These are best suited to single mail-out surveys rather than prospective surveys because they require that all participants are aware of the survey at the same time. Press releases are also more suited to larger-scale surveys such as a survey commissioned by a PCT. Press releases could be sent to local newspapers and magazines to broadcast the survey to the wider population. A Communications Department should be approached with whom the survey manager can collaborate with.

### **11.2. Study website**

This is more important when online methods are to be utilised (in order to host an online survey) but it can also act as a central information resource. It may just be a dedicated page on a hospital or hospice website.

### **11.3. Local awareness-raising**

Further awareness-raising can be achieved through local voluntary organisations. For instance, links with local charitable organisations and community centres may be especially helpful in both raising awareness and increasing response. With permission, it may be possible to display survey posters in such locations.

### **11.4. Alerting health and social care staff**

To further broadcast the survey and prepare health and social care staff for potential questions from those invited to complete questionnaires, it is particularly important that staff working in the data collection sites are aware about the survey. This might be achieved through meetings with Specialist Palliative Care and other clinical staff, commissioners and PCT/hospital/care home representatives for end of life care. In a PCT-wide survey, it might be necessary to draft a letter that can be sent to GPs and care homes.

## **12. Accessing the views of black and minority ethnic groups**

To ensure that the survey is representative of the population, it might be necessary to employ techniques to increase response from members of black and minority ethnic (BME) groups. As is often the case in population surveys, VOICES surveys achieve a very low response from members of BME groups. A previous VOICES survey attempted to address this issue by providing translated versions of the questionnaire but this did not significantly increase response in BME populations<sup>3</sup>. In the same study, focus groups with members of BME populations suggested that face-to-face interviews would be the most appropriate method and most likely to encourage non-English speakers to take part in a survey.

Due to financial resources, face-to-face interviews were not possible in the IMPROVE Survey but a telephone interpreting service was provided. Although only one respondent used this facility, it is still good practice to offer such a service. This might be achieved by collaborating with existing local services such as a hospital interpreting service. However, with a larger survey, such as one managed by a PCT where there might be reduced access to interpreting services, collaboration with an external organisation might be necessary. Lessons from the IMPROVE Survey suggest that take up of such a service is likely to be low (even though the IMPROVE Survey was conducted in an ethnically diverse population) and so there is unlikely to be a considerable cost associated with this approach.

If interpreters are to be used, it is important they are provided with training about the survey and the process of informed consent, as well as being given a glossary of key terms within the questionnaire. Potential participants can be directed to an interpreting service via a language support document printed in the predominant languages in the data collection sites.

### **12.1. Awareness-raising and advertising**

A targeted local advertising and awareness-raising campaign can be used to raise the profile of the survey among BME communities. This can be achieved by developing relationships between the survey team and BME communities by establishing links with local organisations and places of worship. It may also be fruitful to provide translated posters which can be displayed in places of worship or local community centres to further broadcast the survey to certain populations, as well as sending press releases to news and radio stations that represent BME groups. Permission must be sought to display such posters.

In the IMPROVE Survey, the response rate among the BME population was very low (2.3%) despite concerted efforts to increase response. However, small group sessions with BME groups were well attended and may indicate that other methods of data collection would be more appropriate, particularly in the form of focus groups using the VOICES questionnaire as a guide. Care should be taken to ensure appropriate structure of such focus groups.



## **13. Analysis**

It is generally advisable to develop an analysis plan before commencing data collection and in developing such a plan it is important to consider the aims of the survey. For instance, whether the aim is to compare experiences and quality of care across care settings or between patient groups (such as cancer compared to non-cancer patients). Sample size may restrict some comparisons because statistical power is required to make statistical comparisons between groups. However, basic frequencies and percentages are likely to suffice in such survey data and still enable comparisons (descriptive rather than statistical) to be made. Consultation with a statistician is advisable at every stage in a VOICES survey and a statistician should be involved in developing an analysis plan.

A typical analysis plan will include analysis of the demographics of the deceased as well as the respondents, such as age at death, sex, place of death and cause of death. Cause of death should be established based on ICD-10 codes and can be used to group deaths by cause (such as cancer, cardiovascular disease and other). Basic descriptive statistics should then be used to explore the quality of care across care settings: addressing each questionnaire item in turn. Simple tests of associations might be conducted to explore relationships between questionnaire items or to assess statistical differences between groups: such as those who died at home compared to in hospital. However, such analyses should only be conducted where there is sufficient statistical power (ascertained via a power calculation to determine sample size) to ensure that the role of chance can be quantified.

Analytical techniques will also depend on the sampling method – if death certificates are used as the sampling frame it is possible to gather other data such as Indices of Deprivation quintile and reliable data on place and cause of death. Further, data reliability may be an issue if place and cause of death data are sourced from the respondent rather than via a reliable sampling frame because it becomes impossible to check for consistency and error (particularly in the case of self-selection).

### **13.1. Data entry**

VOICES-SF has been designed to facilitate automated data entry which is associated with a lower risk of error than hand data entry. However, this necessitates access to an automated reader. In the absence of such a service, double data entry is recommended in order to check for inconsistencies and increase accuracy.

### **13.2. Data cleaning**

Once all the data have been collected and collated into one master database (such as with Excel/SPSS/STATA), the data must be cleaned in order to detect any incorrect records and to check for inconsistencies in the way the data were entered into the database. It may be necessary to conduct spot checks in a pre-defined proportion by comparing database entries with the returned questionnaire.

Other data cleaning techniques involve searching for outliers or rogue data points by checking frequencies, sorting data in the database by a known variable rather than by ID, calculating measures of central tendency (mean, median and mode) or producing scatterplots. These methods can identify outliers which may indicate data entry errors necessitating re-examination of the original questionnaire.

### **13.3. Data coding**

Firstly, it is important to check that missing data are coded as such, so that they are accounted for in the analysis. Data coding may also aid analysis by making it possible to collapse response categories where there is a theoretical rationale for doing so. It might also be appropriate to recode 'don't know' responses as missing if the intention is to interpret responses as a continuous variable (such as the 'excellent', 'good', 'fair', 'poor' continuum).

### **13.4. Dealing with non-response**

In surveys, high response rates are important where the aim is to make generalisations to the wider population from which the sample is drawn. However, in all survey research, and post-bereavement surveys being no exception, response rates are usually low. Although there have been variations in the response rates for previous VOICES surveys, there is a trend for reducing response rates over time with more recent surveys yielding the lowest response rates. The IMPROVE Survey trialled two different recruitment approaches to determine the most ethically appropriate recruitment method associated with the highest response rate. Using the best method, response rates were 38% and 42% in the two participating PCTs.

Because the response rates in all previous VOICES surveys (35-50%) are low, the risk of bias ('non-response bias') is increased because responders might be different to non-responders on parameters that affect the way that they complete the questionnaire. It is therefore prudent to estimate the degree of non-response bias by comparing variables which are known in both the responders and the non-responders. For example, whether responders (and their associated decedents) were statistically significantly different on parameters such as age, sex, deprivation score, place of death and cause of death. Differences between groups should be assessed with inferential statistics such as via Chi Square for nominal data or t-tests for continuous data.

Although unit non-response (as discussed above) can be assessed using simple inferential statistics, it can also be somewhat overcome using imputation methods. This involves matching non-responders with responders based on known characteristics such as age at death, sex, place of death and cause of death. The questionnaire responses for the matched responder can then be 'imputed' to its respective, matched non-responder.

A further source of missing data in a questionnaire survey is caused by item non-response where participants do not respond to certain questions. This can also be dealt with using

imputation by again matching a participant who does not respond to a particular item, with a demographically similar participant who did answer. In the IMPROVE Survey, imputation was conducted for four deaths where ONS did not have a record of the place of death.

Sample weights may also be applied to the data to increase the 'weight' or influence that certain responders have on the analysis. In the IMPROVE Survey, and for the first time in a VOICES survey, weights were applied to the entire dataset in order to address the under-representation of particular groups by increasing the influence that certain responders had in the analysis. Weights were based on age at death, sex, place of death and cause of death.

The methods outlined above can only be considered if there are known parameters for the non-responders. If health service records or death certificates are used as the sampling frame and informants/relatives are invited to take part, then certain factors will be known about all deaths identified. However, if self-selection is used, no information will be held on those who do not contact the survey team for a copy of the questionnaire. Therefore, methods of dealing with both item and unit non-response are not available.

It is advisable to seek advice from a statistician or specialist in statistics before embarking on either sample weighting or imputation of data.

## **14. Dissemination of survey findings**

A dissemination plan should be pre-defined to ensure that results of the survey reach local health care staff, commissioners, policymakers and the local population. This might be best achieved through a local conference or by organising a series of seminars as well as an accessible lay summary for use in various newsletters or other written media.

A dissemination plan should also cover the future uses of the data such as to define priorities for further research within the Trust/healthcare organisation or to inform future audits of practice.

Lastly, it will also be important to return a results summary to respondents who expressed a desire to receive it (by completing the feedback form). This might take the form of a newsletter covering the salient points from the survey itself (including aims and design) and an overview of the main findings.

## **15. In Summary**

Although not always research-focused, locally-led VOICES surveys should maintain good research practice by:

- ✓ Being based on a pre-defined protocol
- ✓ Taking advice and support from experts in survey design and management
- ✓ Upholding ethical practice for research and evaluation
- ✓ Carefully considering the survey aims and objectives in order to ensure that the findings meet the needs of those who commission the survey
- ✓ Establishing robust and theoretically driven eligibility criteria
- ✓ Choosing the most appropriate sampling strategy to meet the survey aims
- ✓ Making efforts to recruit a representative sample by attempting to increase response among BME populations
- ✓ Ensuring that participants have access to support services should they experience distress
- ✓ Working with a statistician or statistics expert at both the survey design and analysis stages
- ✓ Ensuring that the findings reach the intended audience

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## **Appendices**

<b>Appendix A – VOICES-Short Form (male version)</b>	<b>19</b>
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# VOICES

## Views Of Informal Carers - Evaluation of Services

This questionnaire is about the care and services received by you and your friend/relative in the last months of his life. The information you give will help us improve care for people who are dying, and for their family and friends. Your views are, therefore, important to us.

We realise this questionnaire may bring back strong memories. If you feel upset or distressed, you do not have to continue with the questionnaire and can stop at any time.

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may not be relevant to you. Please fill in as much of the questionnaire as you can.

**Your answers to these questions will be treated as strictly confidential. No names will be used in the reports we write.**

### **Instructions**

As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes, like this . If you make a mistake or wish to change your answer, cross through the answer you do NOT want, like this .

If you would rather not answer one of the questions, please go on to the next one.

We are very interested in what you have to say. Please continue on extra sheets if necessary.

**Q1 How long had he been ill before he died?**

*Tick one only*

- He was not ill - he died suddenly
- Less than 24 hours
- One day or more, but less than one week
- One week or more, but less than one month
- One month or more, but less than six months
- Six months or more, but less than one year
- One year or more

If he died suddenly with no illness or time for care, **please go to Q38**. Otherwise, please continue with the questions below.

**Q2 Did he spend any time at home during the last three months of life?**

*Tick one only*

- Yes – **go to Q3**
- He was in a care home for the whole 3 months – **go to Q12**
- No – **go to Q24**

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## Care at Home

**These questions are about care at home – not in a care home.**

**Q3 When he was at home in the last three months of life, did he get any help at home from any of the services listed below?**

These may be provided by different organisations, such as voluntary organisations, a private agency or social services.

*Tick all that apply*

- A district or community nurse (a nurse in uniform who comes to the house)
- A Macmillan nurse, hospice home care nurse or specialist (a palliative care nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform)
- A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient)
- Any other nurse at home
- Home care worker, home care aide or home help

- Social worker/support worker
- Counsellor
- Religious leader
- Meals-on-wheels or other home delivered meals
- Hospice at home
- Occupational therapist (OT)
- Rapid response team (a team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)
- He did not receive any care
- Don't know
- Something else - please write in the space below:

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**Q4 When he was at home in the last three months of life, did all these services work well together?**

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- He did not receive any care
- Don't know

Please feel free to make comments in the space below:

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**Q5 Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him?**

- Yes, we got as much support as we wanted
- Yes, we got some support but not as much as we wanted
- No, although we tried to get more help
- No, but we did not ask for more help
- We did not need help

Please feel free to make comments in the space below:

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**Q6 During the last three months of his life, while he was at home, how well was his pain relieved?**

*Tick one only*

- Does not apply – he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

Please feel free to make comments in the space below:

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# Urgent Care Provided Out of Hours

**Q7 In the last three months of life, while he was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?**

*Tick one only*

- Not at all in the last 3 months – **go to Q12**
- Once or twice – **go to Q8**
- Three or four times – **go to Q8**
- Five times or more – **go to Q8**
- Don't know – **go to Q12**

**Q8 The last time this happened, who did he contact, or who was contacted on his behalf?**

*Tick all that apply*

- His GP or the out-of-hours number
- NHS Direct
- District nurses
- Macmillan nurses
- He used his 'lifeline' pendant
- A hospice
- 999
- Something else – please write in the space below:

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**Q9 What happened as a result? Was he...**

*Tick one only*

- Visited by his GP at home
- Visited by another GP at home
- Visited by a nurse at home
- Visited by a hospice doctor at home

- Given medical advice over the telephone
- Given another number to ring to get medical advice
- Advised to go to an out-of-hours GP surgery
- Advised to go to the GP surgery when it opened
- Advised to go to an Accident and Emergency Department at a hospital
- Advised to call 999
- Something else – please write in the space below:

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**Q10 In your opinion, was this the right thing for them to do, or not?**

*Tick one only*

- Yes
- No
- Not sure

**Q11 Overall, do you feel that the care he got when he needed care urgently in the evenings or weekends in the last three months of life was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

# District and Community Nurses

If he had care in the last 3 months from district and community nurses, **go to Q12.**

If he did not, **go to Q15.**

**Q12 How often did the district or community nurses visit (at the most frequent time)?**

*Tick one only*

- More than once a day
- Every day
- 2-6 times a week
- Once a week
- 2-3 times a month
- Less often
- Don't know

**Q13 How much of the time was he treated with respect and dignity by the district and community nurses?**

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**Q14 Overall, do you feel that the care he got from the district and community nurses in the last three months of life was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

---

## Care from the GP

**Q15 In the last 3 months, how often did he see the GP he preferred to see?**

*Tick one only*

- Always or almost always
- A lot of the time
- Some of the time
- Never or almost never
- He didn't try to see a particular GP
- He did not need to see a GP – **go to Q20**

**Q16 How much of the time was he treated with respect and dignity by the GPs?**

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**Q17** Were you able to discuss any worries and fears you may have had about his condition, treatment or tests with the GPs?

*Tick one only*

- I had no worries or fears to discuss
- Yes, I discussed them as much as I wanted
- Yes, I discussed them, but not as much as I wanted
- No, although I tried to discuss them
- No, but I did not try to discuss them

**Q18** Overall, if the GP visited him at home in the last three months, how easy or difficult was it to get him/her to visit?

*Tick one only*

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- Don't know
- He wanted the GPs to visit but they would not visit
- Does not apply – the GP did not need to visit
- Don't know

**Q19** Overall, do you feel that the care he got from the GP in the last three months of life was:

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

Please feel free to make comments in the space below:

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## Care Homes

**Q20** Did he live or stay in a care home at any time during his last three months of life?

*Tick one only*

- Yes, he was in a care home – please write the name of the care home in the space below:

- 
- No – **go to Q24**
  - Don't know – **go to Q24**

**Q21** How much of the time was he treated with respect and dignity by the staff at the care home?

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**Q22** During the last three months of his life, while he was in the care home, how well was his pain relieved?

*Tick one only*

- Does not apply - he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

**Q23** Overall, do you feel that the care he got from the care home in the last three months of life was:

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

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## Last Hospital Admission

**Q24** Did he stay in hospital at any time during his last three months of life?

*Tick one only*

- Yes – please write the name of the last hospital he stayed in, in the space below:  
  
\_\_\_\_\_
- No – **go to Q29**
- Don't know – **go to Q29**

**Q25** During his last hospital admission, how much of his time was he treated with respect and dignity by the hospital doctors and nurses?

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Always           |
| <input type="checkbox"/> | <input type="checkbox"/> | Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Never            |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know       |

**Q26** During this last hospital admission, how well was his pain relieved?

*Tick one only*

- Does not apply – he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

**Q27** Did the hospital services work well together with his GP and other services outside of the hospital?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- Don't know

**Q28 Overall, do you feel that the care he got from the staff in the hospital on that admission was:**

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |            |
|--------------------------|--------------------------|------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Excellent  |
| <input type="checkbox"/> | <input type="checkbox"/> | Good       |
| <input type="checkbox"/> | <input type="checkbox"/> | Fair       |
| <input type="checkbox"/> | <input type="checkbox"/> | Poor       |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know |

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## Last Hospice Admission

**Q29 Did he stay in a hospice at any time during his last three months of life?**

*Tick one only*

- Yes – please write the name of the last hospice he stayed in, in the space below:

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- No – **go to Q33**  
 Don't know – **go to Q33**

**Q30 How much of the time was he treated with respect and dignity by the hospice doctors and nurses?**

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Always           |
| <input type="checkbox"/> | <input type="checkbox"/> | Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Never            |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know       |

**Q31 During the last three months of his life, while he was in the hospice, how well was his pain relieved?**

*Tick one only*

- Does not apply - he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

**Q32 Overall, do you feel that the care he got from the staff in the hospice was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

# Experiences in the Last 2 Days of Life

**Q33 During his last two days of life was he:**

*Tick one only*

- At home all the time
- In a care home all the time
- In a hospital all the time
- In a hospice all the time
- Other – please write in the space below:

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**Q34 How much of the time was he treated with respect and dignity in the last two days of life?**

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Always           |
| <input type="checkbox"/> | <input type="checkbox"/> | Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Never            |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know       |

**Q35 Please look at the following statements and tick the answer box that corresponds most with your opinion about the help he received in the last two days of life**

*Tick one box for each question (a - c)*

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	Don't know
(a) There was enough help available to meet his personal care needs (such as toileting needs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) The bed area and surrounding environment had adequate privacy for him	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q36 During the last two days, how do you assess the overall level of support given in the following areas from those caring for him?**

*Tick one box for each question (a - e)*

	Excellent	Good	Fair	Poor	Does not apply	Don't know
(a) Relief of pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Relief of symptoms other than pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Support to stay where he wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Circumstances Surrounding His Death

## Q37 Did he know he was likely to die?

*Tick one only*

- Yes, certainly
- Yes, probably
- Probably not
- No, definitely
- Not sure

## Q38 In your opinion, did the person who told him he was likely to die break the news to him in a sensitive and caring way?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know
- Does not apply – they did not know he was dying
- Does not apply – they did not tell him he was dying

## Q39 Were you contacted soon enough to give you time to be with him before he died?

*Tick one only*

- Yes
- No
- I was there already
- It was not clear that he was going to die soon
- I couldn't have got there anyway

## Q40 Where did he die?

*Tick one only*

- In his own home
- In the home of another family member or friend
- In a hospital ward – please write the name of the hospital in the space below:

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- In a hospital Accident and Emergency Department – please write the name of the hospital in the space below:

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- In a hospital Intensive Care Unit – please write the name of the hospital in the space below:

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- In a hospice – please write the name of the hospice in the space below:

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- In a care home – please write the name of the care home in the space below:

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- In an ambulance on the way to hospital/hospice

- Somewhere else – please write in the space below:

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**Q41 Did he ever say where he would like to die?**

*Tick one only*

- Yes – **go to Q42**
- No – **go to Q44**
- Not sure – **go to Q44**

**Q42 Where did he say that he would like to die?**

*Tick one only*

- At home
- In a hospice
- In a hospital
- In a care home
- He said he did not mind where he died
- He changed his mind about where he wanted to die
- Somewhere else – please write in the space below:  

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**Q43 Did the health care staff have a record of this?**

*Tick one only*

- Yes
- No
- Not sure

**Q44 Do you think he had enough choice about where he died?**

*Tick one only*

- Yes
- No
- Not sure
- He died suddenly

**Q45 On balance, do you think that he died in the right place?**

*Tick one only*

- Yes
- No
- Not sure

**Q46 Were you or his family given enough help and support by the healthcare team at the actual time of his death?**

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know

**Q47 After he died, did staff deal with you or his family in a sensitive manner?**

*Tick one only*

- Yes
- No
- Don't know
- Does not apply, I didn't have any contact with the staff

Please feel free to make comments in the space below:  

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**Q48 Looking back over the last three months of his life, was he involved in decisions about his care as much as he would have wanted?**

*Tick one only*

- He was involved as much as he wanted to be
- He would have liked to be more involved
- He would have liked to be less involved
- Don't know

**Q49** Looking back over the last three months of his life, were you involved in decisions about his care as much as you would have wanted?

*Tick one only*

- I was involved as much as I wanted to be
- I would have liked to be more involved
- I would have liked to be less involved
- Don't know

**Q50** Were any decisions made about his care that he would not have wanted?

*Tick one only*

- Yes
- No
- Don't know

Please feel free to make comments in the space below:

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**Q51** Overall, and taking all services into account, how would you rate his care in the last three months of life?

*Tick one only*

- Outstanding
- Excellent
- Good
- Fair
- Poor
- Don't know

**Q52** Since he died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his illness and death?

*Tick one only*

- Yes
- No, but I would have liked to
- No, but I did not want to anyway
- Not sure

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## Information About You Both

**Q53** What was your relationship to him?  
Were you his:

*Tick one only*

- Wife/Partner
- Son/Daughter
- Brother/Sister
- Son-in-law/Daughter-in-law
- Parent
- Other relative
- Friend
- Neighbour
- Staff in care home
- Warden(sheltered accommodation)
- Other official
- Someone else

**Q54** What is your age?

- 18-19
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90+

**Q55** Are you:

- Male
- Female

**Q56** Please could you indicate which ethnic group you belong to:

*Tick one only*

**White**

- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other white background

**Mixed/Multiple ethnic group**

- White & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background

**Asian/Asian British**

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian background

**Black/African/Caribbean/Black British**

- African
- Caribbean
- Any other black/African/Caribbean background

**Other ethnic group**

- Arab
- Any other ethnic group

**Q57** Please could you indicate which ethnic group he belonged to:

*Tick one only*

**White**

- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other white background

**Mixed/Multiple ethnic group**

- White & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background

**Asian/Asian British**

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian background

**Black/African/Caribbean/Black British**

- African
- Caribbean
- Any other black/African/Caribbean background

**Other ethnic group**

- Arab
- Any other ethnic group

**Q58** What was his age when he died?

- 18–19
- 20–29
- 30–39
- 40–49
- 50–59
- 60–69
- 70–79
- 80–89
- 90+

**Q59** What was his religion?

- No religion
- Christian (all denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion – please write in the space below:

**What, if anything, was good about the care?**

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**What, if anything, was bad about the care?**

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Thank you for taking the time to complete this questionnaire.

We would be very grateful if you could return it to us in the Freepost envelope provided.

# VOICES

## Views Of Informal Carers - Evaluation of Services

This questionnaire is about the care and services received by you and your friend/relative in the last months of her life. The information you give will help us improve care for people who are dying, and for their family and friends. Your views are, therefore, important to us.

We realise this questionnaire may bring back strong memories. If you feel upset or distressed, you do not have to continue with the questionnaire and can stop at any time.

We are interested in finding out the experiences of all people who have died whether suddenly, after a short illness, or after a long illness. We also think it is important to find out about the care you and the family received at the time of death and in the months since then. Some of the questions may not be relevant to you. Please fill in as much of the questionnaire as you can.

**Your answers to these questions will be treated as strictly confidential. No names will be used in the reports we write.**

### **Instructions**

As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box or boxes, like this . If you make a mistake or wish to change your answer, cross through the answer you do NOT want, like this .

If you would rather not answer one of the questions, please go on to the next one.

We are very interested in what you have to say. Please continue on extra sheets if necessary.

**Q1 How long had she been ill before she died?**

*Tick one only*

- She was not ill - she died suddenly
- Less than 24 hours
- One day or more, but less than one week
- One week or more, but less than one month
- One month or more, but less than six months
- Six months or more, but less than one year
- One year or more

If she died suddenly with no illness or time for care, **please go to Q38**. Otherwise, please continue with the questions below.

**Q2 Did she spend any time at home during the last three months of life?**

*Tick one only*

- Yes – **go to Q3**
- She was in a care home for the whole 3 months – **go to Q12**
- No – **go to Q24**

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## Care at Home

**These questions are about care at home – not in a care home.**

**Q3 When she was at home in the last three months of life, did she get any help at home from any of the services listed below?**

These may be provided by different organisations, such as voluntary organisations, a private agency or social services.

*Tick all that apply*

- A district or community nurse (a nurse in uniform who comes to the house)
- A Macmillan nurse, hospice home care nurse or specialist (a palliative care nurse who visits or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform)
- A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient)
- Any other nurse at home
- Home care worker, home care aide or home help

- Social worker/support worker
- Counsellor
- Religious leader
- Meals-on-wheels or other home delivered meals
- Hospice at home
- Occupational therapist (OT)
- Rapid response team (a team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)
- She did not receive any care
- Don't know
- Something else - please write in the space below:

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**Q4** When she was at home in the last three months of life, did all these services work well together?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- She did not receive any care
- Don't know

Please feel free to make comments in the space below:

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**Q5** Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for her?

- Yes, we got as much support as we wanted
- Yes, we got some support but not as much as we wanted
- No, although we tried to get more help
- No, but we did not ask for more help
- We did not need help

Please feel free to make comments in the space below:

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**Q6** During the last three months of her life, while she was at home, how well was her pain relieved?

*Tick one only*

- Does not apply – she did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

Please feel free to make comments in the space below:

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# Urgent Care Provided Out of Hours

**Q7 In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent in the evening or at the weekend?**

*Tick one only*

- Not at all in the last 3 months – **go to Q12**
- Once or twice – **go to Q8**
- Three or four times – **go to Q8**
- Five times or more – **go to Q8**
- Don't know – **go to Q12**

**Q8 The last time this happened, who did she contact, or who was contacted on her behalf?**

*Tick all that apply*

- Her GP or the out-of-hours number
- NHS Direct
- District nurses
- Macmillan nurses
- She used her 'lifeline' pendant
- A hospice
- 999
- Something else – please write in the space below:

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**Q9 What happened as a result? Was she...**

*Tick one only*

- Visited by her GP at home
- Visited by another GP at home
- Visited by a nurse at home
- Visited by a hospice doctor at home

- Given medical advice over the telephone
- Given another number to ring to get medical advice
- Advised to go to an out-of-hours GP surgery
- Advised to go to the GP surgery when it opened
- Advised to go to an Accident and Emergency Department at a hospital
- Advised to call 999
- Something else – please write in the space below:

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**Q10 In your opinion, was this the right thing for them to do, or not?**

*Tick one only*

- Yes
- No
- Not sure

**Q11 Overall, do you feel that the care she got when she needed care urgently in the evenings or weekends in the last three months of life was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

# District and Community Nurses

If she had care in the last 3 months from district and community nurses, **go to Q12.**

If she did not, **go to Q15.**

**Q12 How often did the district or community nurses visit (at the most frequent time)?**

*Tick one only*

- More than once a day
- Every day
- 2-6 times a week
- Once a week
- 2-3 times a month
- Less often
- Don't know

**Q13 How much of the time was she treated with respect and dignity by the district and community nurses?**

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**Q14 Overall, do you feel that the care she got from the district and community nurses in the last three months of life was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

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## Care from the GP

**Q15 In the last 3 months, how often did she see the GP she preferred to see?**

*Tick one only*

- Always or almost always
- A lot of the time
- Some of the time
- Never or almost never
- She didn't try to see a particular GP
- She did not need to see a GP – **go to Q20**

**Q16 How much of the time was she treated with respect and dignity by the GPs?**

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**Q17** Were you able to discuss any worries and fears you may have had about her condition, treatment or tests with the GPs?

*Tick one only*

- I had no worries or fears to discuss
- Yes, I discussed them as much as I wanted
- Yes, I discussed them, but not as much as I wanted
- No, although I tried to discuss them
- No, but I did not try to discuss them

**Q18** Overall, if the GP visited her at home in the last three months, how easy or difficult was it to get him/her to visit?

*Tick one only*

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- Don't know
- She wanted the GPs to visit but they would not visit
- Does not apply – the GP did not need to visit
- Don't know

**Q19** Overall, do you feel that the care she got from the GP in the last three months of life was:

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

Please feel free to make comments in the space below:

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## Care Homes

**Q20** Did she live or stay in a care home at any time during her last three months of life?

*Tick one only*

- Yes, she was in a care home – please write the name of the care home in the space below:

- 
- No – **go to Q24**
  - Don't know – **go to Q24**

**Q21** How much of the time was she treated with respect and dignity by the staff at the care home?

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**Q22** During the last three months of her life, while she was in the care home, how well was her pain relieved?

*Tick one only*

- Does not apply - she did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

**Q23** Overall, do you feel that the care she got from the care home in the last three months of life was:

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

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## Last Hospital Admission

**Q24** Did she stay in hospital at any time during her last three months of life?

*Tick one only*

- Yes – please write the name of the last hospital she stayed in, in the space below:  
  
\_\_\_\_\_
- No – **go to Q29**
- Don't know – **go to Q29**

**Q25** During her last hospital admission, how much of the time was she treated with respect and dignity by the hospital doctors and nurses?

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Always           |
| <input type="checkbox"/> | <input type="checkbox"/> | Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Never            |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know       |

**Q26** During this last hospital admission, how well was her pain relieved?

*Tick one only*

- Does not apply – she did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

**Q27** Did the hospital services work well together with her GP and other services outside of the hospital?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- Don't know

**Q28 Overall, do you feel that the care she got from the staff in the hospital on that admission was:**

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |            |
|--------------------------|--------------------------|------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Excellent  |
| <input type="checkbox"/> | <input type="checkbox"/> | Good       |
| <input type="checkbox"/> | <input type="checkbox"/> | Fair       |
| <input type="checkbox"/> | <input type="checkbox"/> | Poor       |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know |

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## Last Hospice Admission

**Q29 Did she stay in a hospice at any time during her last three months of life?**

*Tick one only*

- Yes – please write the name of the last hospice she stayed in, in the space below:

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- No – **go to Q33**  
 Don't know – **go to Q33**

**Q30 How much of the time was she treated with respect and dignity by the hospice doctors and nurses?**

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Always           |
| <input type="checkbox"/> | <input type="checkbox"/> | Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Never            |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know       |

**Q31 During the last three months of her life, while she was in the hospice, how well was her pain relieved?**

*Tick one only*

- Does not apply - she did not have any pain  
 Completely, all of the time  
 Completely, some of the time  
 Partially  
 Not at all  
 Don't know

**Q32 Overall, do you feel that the care she got from the staff in the hospice was:**

*Tick one only*

- Excellent  
 Good  
 Fair  
 Poor  
 Don't know

# Experiences in the Last 2 Days of Life

**Q33 During her last two days of life was she:**

*Tick one only*

- At home all the time
- In a care home all the time
- In a hospital all the time
- In a hospice all the time
- Other – please write in the space below:

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**Q34 How much of the time was she treated with respect and dignity in the last two days of life?**

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                   |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Always           |
| <input type="checkbox"/> | <input type="checkbox"/> | Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> | Never            |
| <input type="checkbox"/> | <input type="checkbox"/> | Don't know       |

**Q35 Please look at the following statements and tick the answer box that corresponds most with your opinion about the help she received in the last two days of life**

*Tick one box for each question (a - c)*

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Does not apply	Don't know
(a) There was enough help available to meet her personal care needs (such as toileting needs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) There was enough help with nursing care, such as giving medicine and helping her find a comfortable position in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) The bed area and surrounding environment had adequate privacy for her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q36 During the last two days, how do you assess the overall level of support given in the following areas from those caring for her?**

*Tick one box for each question (a - e)*

	Excellent	Good	Fair	Poor	Does not apply	Don't know
(a) Relief of pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Relief of symptoms other than pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Support to stay where she wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Circumstances Surrounding Her Death

## Q37 Did she know she was likely to die?

*Tick one only*

- Yes, certainly
- Yes, probably
- Probably not
- No, definitely
- Not sure

## Q38 In your opinion, did the person who told her she was likely to die break the news to her in a sensitive and caring way?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know
- Does not apply – they did not know she was dying
- Does not apply – they did not tell her she was dying

## Q39 Were you contacted soon enough to give you time to be with her before she died?

*Tick one only*

- Yes
- No
- I was there already
- It was not clear that she was going to die soon
- I couldn't have got there anyway

## Q40 Where did she die?

*Tick one only*

- In her own home
- In the home of another family member or friend
- In a hospital ward – please write the name of the hospital in the space below:

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- In a hospital Accident and Emergency Department – please write the name of the hospital in the space below:

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- In a hospital Intensive Care Unit – please write the name of the hospital in the space below:

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- In a hospice – please write the name of the hospice in the space below:

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- In a care home – please write the name of the care home in the space below:

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- In an ambulance on the way to hospital/hospice

- Somewhere else – please write in the space below:

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**Q41 Did she ever say where she would like to die?**

*Tick one only*

- Yes – **go to Q42**
- No – **go to Q44**
- Not sure – **go to Q44**

**Q42 Where did she say that she would like to die?**

*Tick one only*

- At home
- In a hospice
- In a hospital
- In a care home
- She said she did not mind where she died
- She changed her mind about where she wanted to die
- Somewhere else – please write in the space below:

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**Q43 Did the health care staff have a record of this?**

*Tick one only*

- Yes
- No
- Not sure

**Q44 Do you think she had enough choice about where she died?**

*Tick one only*

- Yes
- No
- Not sure
- She died suddenly

**Q45 On balance, do you think that she died in the right place?**

*Tick one only*

- Yes
- No
- Not sure

**Q46 Were you or her family given enough help and support by the healthcare team at the actual time of her death?**

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know

**Q47 After she died, did staff deal with you or her family in a sensitive manner?**

*Tick one only*

- Yes
- No
- Don't know
- Does not apply, I didn't have any contact with the staff

Please feel free to make comments in the space below:

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**Q48 Looking back over the last three months of her life, was she involved in decisions about her care as much as she would have wanted?**

*Tick one only*

- She was involved as much as she wanted to be
- She would have liked to be more involved
- She would have liked to be less involved
- Don't know

**Q49** Looking back over the last three months of her life, were you involved in decisions about her care as much as you would have wanted?

*Tick one only*

- I was involved as much as I wanted to be
- I would have liked to be more involved
- I would have liked to be less involved
- Don't know

**Q50** Were any decisions made about her care that she would not have wanted?

*Tick one only*

- Yes
- No
- Don't know

Please feel free to make comments in the space below:

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**Q51** Overall, and taking all services into account, how would you rate her care in the last three months of life?

*Tick one only*

- Outstanding
- Excellent
- Good
- Fair
- Poor
- Don't know

**Q52** Since she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about her illness and death?

*Tick one only*

- Yes
- No, but I would have liked to
- No, but I did not want to anyway
- Not sure

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## Information About You Both

**Q53** What was your relationship to her?  
**Were you her:**

*Tick one only*

- Husband/Partner
- Son/Daughter
- Brother/Sister
- Son-in-law/Daughter-in-law
- Parent
- Other relative
- Friend
- Neighbour
- Staff in care home
- Warden(sheltered accommodation)
- Other official
- Someone else

**Q54** What is your age?

- 18-19
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90+

**Q55** Are you:

- Male
- Female

**Q56 Please could you indicate which ethnic group you belong to:**

*Tick one only*

**White**

- English/Welsh/Scottish/Northern Irish/  
British
- Irish
- Gypsy or Irish Traveller
- Any other white background

**Mixed/Multiple ethnic group**

- White & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background

**Asian/Asian British**

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian background

**Black/African/Caribbean/Black British**

- African
- Caribbean
- Any other black/African/Caribbean  
background

**Other ethnic group**

- Arab
- Any other ethnic group

**Q57 Please could you indicate which ethnic group she belonged to:**

*Tick one only*

**White**

- English/Welsh/Scottish/Northern Irish/  
British
- Irish
- Gypsy or Irish Traveller
- Any other white background

**Mixed/Multiple ethnic group**

- White & Black Caribbean
- White & Black African
- White & Asian
- Any other mixed background

**Asian/Asian British**

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian background

**Black/African/Caribbean/Black British**

- African
- Caribbean
- Any other black/African/Caribbean  
background

**Other ethnic group**

- Arab
- Any other ethnic group

**Q58 What was her age when she died?**

- 18–19
- 20–29
- 30–39
- 40–49
- 50–59
- 60–69
- 70–79
- 80–89
- 90+

**Q59 What was her religion?**

- No religion
- Christian (all denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion – please write in the  
space below:





Thank you for taking the time to complete this questionnaire.

We would be very grateful if you could return it to us in the Freepost envelope provided.

**Study ID Number:**

Date

[ADDRESS TO FIT IN ENVELOPE WINDOW]

Dear [title] [surname],

**Invitation to help with the VOICES survey of experiences of care in the last months of life**

**If you would like to receive this information in large print please call xxx (weekdays xam-xpm)**

We are writing to you because you registered the death of [title] [first name and surname of the deceased]. We appreciate that this may be a very difficult time but we would like to invite you to take part in the VOICES Survey of experiences of care in the last months of life. The results will be used to improve care and services for people and their families at the end of life. Xxx is funding the survey and our survey team xxx is working alongside xxx to carry out this study. The Office for National Statistics is managing the administrative side of the project and identified you from their deaths database. They are contacting you on our behalf and will not release any of your personal details to us.

Taking part in the VOICES Survey involves completing a questionnaire called VOICES (Views of Informal Carers – Evaluation of Services) which asks about experiences in the last months of life, care received from health and social services and whether care needs were fully met. This takes about 30 minutes.

It is up to you whether you would like to take part in the survey. We have enclosed the VOICES questionnaire and an information sheet about the study so you can read more about it. This will help you to make an informed decision about whether you want to get involved. Further details can be obtained by calling xxx (one of the survey team) on xxx (weekdays xam-xpm) or by looking on the study website at: [www.xxx](http://www.xxx)

If you do decide to take part we ask that you complete the enclosed VOICES questionnaire and then return it in the FREEPOST envelope to xxx (no stamp is needed).

Alternatively, you can complete the questionnaire online by going to [www.xxx](http://www.xxx), clicking on the link 'Complete VOICES online' and entering the following user name and password:

User name:

Password:

You will then be asked to enter your unique and anonymous ID number, this is:

Online ID number

When you have finished completing the questionnaire online, it will be automatically emailed back to the survey team at xxx. The researchers will not be able to identify you from the questionnaire.

If you do not think that you are the best person to complete the questionnaire, please pass this on to whoever you feel would be the best person to complete it.

If you do not wish to participate you can let the Office for National Statistics know by filling in and returning the reply slip and in the FREEPOST envelope enclosed. This will ensure that you do not receive reminder letters.

Your views are very important and will help to improve future care for patients and families in England. We apologise if this enquiry has caused you any distress and hope this letter does not bring back too many painful memories. Thank you for taking the time to read this letter and we very much hope that you feel able to take part in this survey.

Yours sincerely,

xxx

xxx



# **VOICES Survey**

## **Experiences of care in the last months of life**

### **INFORMATION LEAFLET**

You are being invited to take part in a questionnaire-based survey using the VOICES questionnaire.

Before you decide to participate, it is important that you understand why the survey is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

If you would like more information or you have any questions, please talk to a member of the survey team on xxx (weekdays xam-xpm). Alternatively, you can visit the survey website at [www.xxx](http://www.xxx).

**Thank you for taking the time to read this. Your views are very important and will be used to help us to provide better care for patients and families in the future. We very much hope you will feel able to contribute.**

Contact us at:  
xxx xxx  
xxx

## **What is the purpose of the VOICES Survey?**

VOICES is a survey of bereaved relatives that uses the VOICES questionnaire which asks about experiences in the last months of life. You are one of xxx people we are contacting who has recently registered the death of a relative or friend and we would like your help. If you decide to help by completing the VOICES questionnaire, your responses will be used to improve local services for people in the last months of life and to compare care and bereavement services to other parts of the country.

Although participation in VOICES will not help you directly, we hope that the information you give us will enable us to improve people's experiences of care at the end of their lives and improve services provided to bereaved relatives and friends.

## **Why have I been chosen?**

You have been chosen to take part because you registered a death in xxx in the past year. We asked The Office for National Statistics (a government department that processes information on the UK population) to select death certificates from their database. To protect your privacy, the Office for National Statistics has contacted you on our behalf.

The Office for National Statistics has not given us any personal information about you. We do not know your name or your address. They have given each person who has been invited to take part, a unique identification number (written on the top left corner of the invitation letter addressed to you). This ensures that the information you provide is totally confidential, in accordance with the Data Protection Act.

## **What will taking part involve?**

- We would like you to fill in a questionnaire called VOICES. This will take around 30 minutes. It asks about the care and support both you and your relative/friend received in the last months of their life and whether your relative/friend's needs were fully met. Your experiences are very important, so please feel free to be completely open and honest.

Most of the questions can be answered by simply ticking the most appropriate box. If you would prefer not to answer a question, please go on to the next one. We would be very grateful for any additional comments that you would like to make in the spaces provided or on the back page.

- Returning the completed questionnaire. We have enclosed a large FREEPOST envelope to be posted back to the research team at xxx. If you lose this envelope you can still return the questionnaire with no charge by posting it to FREEPOST xxx.

- If you prefer, you can complete an electronic version of the questionnaire on the internet. If you would like to do so, please go to [www.xxxxx](http://www.xxxxx). When you have loaded the webpage, you will need to click on the link 'Complete VOICES online'. Then enter the user name and password found on the second page of the letter of invitation you received with this information sheet. You will then be asked to enter your unique and anonymous ID number also found on the second page of the invitation letter. The survey team will not be able to identify you from this ID number. Any information you provide us or comments that you write in the questionnaire will remain entirely confidential. When you have finished completing the questionnaire online, it will be automatically emailed back to the survey team at xxx.

The survey team are more than happy to provide extra help and support in completing the questionnaire. If you would like help, or if you have any questions, please call us on xxx (weekdays xxam-xxpm).

If English is not your first language and you would like interpreter services, we have a language telephone line you can call on xxx. We can then arrange for an interpreter to call you back.

### **What should I do if I want to take part?**

If you would like to take part, please complete the questionnaire and then return it to xxx using the FREEPOST envelope enclosed. You do not need a stamp. Alternatively, complete the questionnaire online (at [www.xxx](http://www.xxx)) and then it will automatically be emailed back to the survey team when you have finished.

If you would like more information about the survey to help you to decide whether you would like to get involved, you can call the survey team on xxx (weekdays xam-xpm) or go to the survey website at [www.xxx](http://www.xxx).

If you do not think that you are the best person to complete the questionnaire, please pass it on to whoever you feel would be the best person to complete it.

### **Do I have to take part?**

Taking part is completely voluntary. If you do decide to take part you may change your mind or choose not to continue in the survey at any time, without having to give a reason for doing so. Please feel free to discuss the survey with your family and friends before you make a decision. If you would like to take part, please complete the questionnaire and return it in the FREEPOST envelope.

However, if you decide not to complete the questionnaire, please return the reply slip so that the Office for National Statistics does not contact you again.

**What are the possible disadvantages of taking part?**

Some people find it distressing to think about the care that their loved ones or close friends received during the last year of their lives. Answering questions about care at the end of life can bring back painful memories. If you find it distressing, you can stop completing the questionnaire at any time and choose not to continue.

We are working with [Cruse Bereavement Care] services, a charitable organisation that provides help and support to those who have lost loved ones. If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire, please call [Cruse Bereavement Care] on xxx (weekdays xam-xpm) 24 hour 7 day answerphone).

**How will the information I give be kept confidential?**

The Office for National Statistics (ONS) will not give us (the survey team) any information which identifies you. You will only be identified by a number that the ONS provided.

All the information collected will be kept strictly confidential within the survey team and secured against unauthorised access. We would also like to make absolutely clear that no names, or other information that could identify you, will be used in any reports we write. You will *not* be asked to include your name on the questionnaire; instead an identification number will be assigned to ensure that you remain anonymous in any reports about the results.

The information collected will be retained and securely stored for 10 years and will then be disposed of securely.

**What if there is a problem or I have a complaint?**

If you have a concern or a complaint about this study you should contact xxx, at xxx:

xxxxxxx  
xxxxxxxxx

If you remain unhappy and wish to complain formally xxx can provide you with details of the xxx Complaints Procedure.

**Who is organising and funding the survey?**

The VOICES survey has been set up by xxx. The Office for National Statistics are organising the survey and recruiting participants and the survey has been funded by xxx.

## **What will happen to the results of the survey?**

Information obtained from the questionnaire will be entered into a database and analysed by the survey team. At the end of the project, the findings will be written up into a report, which will be submitted to xxx. The results will be available to the public. We cannot promise the project will help you but the information we get from this project will help improve the quality of end of life care provided in England.

No identifying information about you will be included in the report or any articles about this survey.

If you would like to see the results of this survey, you can visit the survey website at [www.xxx](http://www.xxx). Alternatively, you can complete the response slip at the bottom of this information sheet and we will send you a copy of the results to the address you give us.

**We understand that coping with the loss of a loved one is not easy and we really appreciate you taking the time to read this information. We are confident that this survey will make a difference to improving the way that care is delivered to people at the end of their lives.**

**Many thanks again.**

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Yes please, I would like to receive feedback on the results of the survey.  
My contact details are:

Your Name (please print clearly)

Your address

**THANK YOU**

# VOICES Survey

## Experiences of care in the last months of life

### REPLY SLIP

ID Number:

If you would prefer NOT to take part in the above survey, please return this form in the pre-paid envelope, so that we do not contact you again.

(Please tick)

You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of survey.

.....  
.....  
.....

**Thank you for taking the time to complete and return this form**

**Study ID Number:**

**Date**

**[ADDRESS TO FIT IN ENVELOPE WINDOW]**

Dear [title] [surname],

**Invitation to help with the VOICES survey about experiences of care in the last months of life**

You may remember that we wrote to you a few weeks ago asking for your help with a survey we are currently conducting with xxx. As we have not heard back from you we are writing again to check whether or not you are willing to take part in this study. If you have responded recently, please accept our apologies for having bothered you.

We would be grateful if you could complete the enclosed questionnaire and return it to xxx in the pre-paid envelope provided. If you do not feel you are the best person to complete the questionnaire, please pass it on to whoever you think may be the best person to take part.

You can complete the questionnaire online if you would prefer. To do this, go to [www.xxx](http://www.xxx), click on the link 'Complete VOICES online' and enter the following user name and password:

**User name:**

**Password:**

You will then be asked to enter your unique and anonymous ID number, this is:

**Online ID number**

If you do not wish to take part in this study please complete the 'REPLY SLIP' and return it in the pre-paid envelope provided. This will ensure that you do not receive any further reminder letters from us.

We apologise for any distress caused by this enquiry and hope that this letter does not bring back too many painful memories. We would like to take the opportunity to thank you for taking the time to read this letter and very much hope you will feel able to take part.



Should you have any questions, please do not hesitate to contact one of the survey team, xxx on xxx (weekdays x-xpm).

We hope you will be happy to take part in this project.

Yours sincerely,

xxx

xxx