

VOICES Redesign  
and Testing to Inform  
a National End of Life  
Care Survey

Final Report for the  
Department of Health

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The views expressed in this report are those of the authors and not necessarily of the Department of Health.

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# Executive Summary

## Background

1. The publication of the Department of Health End of Life Strategy in 2008 signalled a revived focus on care at the end of life. The Strategy outlined a series of areas where changes to end of life care should be made. There was an expectation that the success of the Strategy would be evaluated by accessing the views of those who use end of life care services. The NHS Outcomes Framework reaffirmed the need to gather patient data to monitor service delivery and inform service improvements.
2. Measurement of the quality of end of life care is problematic for several important ethical and logistical reasons. Proxy reports are a well-recognised method of collecting views about care during this period. The VOICES questionnaire is a questionnaire about health and social services provided at the end of life, and is completed by bereaved relatives.
3. There is a lack of consensus as to the best method of recruitment to a VOICES survey and various NHS Ethics Committees have taken different decisions in the past. There is no evidence to inform whether it is best for respondents to receive a questionnaire when they receive the invitation to participate, or should receive it later after making a request to be sent it.

## Aims and Objectives

4. To adapt and test VOICES as a measure of the quality of end of life care which reflects the key features of the DH End of Life Care Strategy.
5. To investigate whether recruitment strategy can impact upon response rates in VOICES surveys.
6. To provide guidance for the planning and execution of future VOICES surveys. To include appropriate methods, required sample sizes to make between-PCT comparisons, methods of increasing response overall and for demographic sub-groups such as BME populations.

## Methods

7. VOICES was redesigned to meet the requirements of the Strategy, a 58 item questionnaire was developed.
8. Stratified sampling was used to recruit a sample of deaths from death certificates via the Office for National Statistics. All adult deaths (aged over 18 years) in Berkshire East and the Isle of Wight PCTs between September 2009 and April 2010 were eligible for inclusion. Coroner-registered deaths were excluded. The sample was stratified according to PCT, place and cause of death to facilitate comparisons.
9. Deaths were assigned to two trial groups: either the 'Single posting' group (where relatives received a copy of VOICES in the first instance) or the 'Opt in' group (where relatives had to request a copy of VOICES).
10. In order to increase response, online methods were used to supplement the paper version of VOICES, a local media campaign was launched and a strategy to increase participation among black and minority (BME) groups was initiated.

## **Main Findings**

11. 473 relatives completed the questionnaire. Response rate in the 'Single posting' group (40%) was statistically significantly higher than in the 'Opt in' group (26% –  $p < .001$ ).
12. Response in BME groups was not increased as a result of the strategy but media promotion appeared to increase overall response in both PCTs.
13. The online version of the questionnaire was used by a considerable proportion of the sample. However, online response was substantially higher in the 'opt in' group where respondents used the online version to bypass the need to request a paper copy of the questionnaire.
14. Mechanisms developed to offer support for questionnaire completion, respond to distress, and manage complaints about care received and the research itself, appeared feasible and effective
15. Weighting of data was required to account for non-response bias.
16. Key differences in responses to questionnaire items were noted between PCTs and for those who died of cancer/CVD/other causes.
17. If PCTs are adopted as the unit of analysis, it may not be possible (due to the size of the population) to make statistical comparisons between PCTs based on place/cause of death. However, with individual PCT/GP Consortium sample sizes greater than 700 and response rates of at least 35%, this is possible. If the place/cause of death comparison within PCTs is not required, smaller sample sizes are acceptable.

## **Recommendations**

18. VOICES-SF is a validated sensitive measure of experiences of end of life care that can detect differences between PCTs, care settings, cause of death and place of death and is therefore the appropriate measurement tool for a national survey of end of life care.
19. The sample should be identified through death certificates (which requires collaboration with ONS) and should employ a stratified sampling design to facilitate analysis based on the comparisons of interest (PCT, cause of death, place of death).
20. The 'single posting' method of recruitment is associated with the highest response rate and is therefore the method of choice. To further increase response, this should be supplemented with an online version of the questionnaire.
21. NHS Ethical Approval may not be necessary if future surveys are not carried out on NHS premises or do not involve NHS patients or staff.
22. A centralised complaints line represents a suitable method of monitoring and dealing with complaints about the research or care provided.
23. Emotional support should be readily available for respondents. This might be best provided by an organisation such as Cruse Bereavement Care.
24. An interpreting service should be available to increase participation among BME groups.
25. Promotional activities may be best focused using a centralised press release issued by the Department of Health.

# 1. Background

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. The main tenets of the Strategy were to:

- raise the profile of end of life care
- reinforce the importance of care planning at the end of life
- coordinate end of life care across care settings
- support the delivery of high quality services in all locations
- increase use of the Liverpool Care Pathway
- involve and support carers
- ensure health and social care staff have the necessary knowledge to provide high quality end of life care.

Work to implement the Strategy has been ongoing in the form of the National End of Life Care Programme. Central to the Strategy is achieving excellence in patient care and improving patient experience and there is an expectation that this will be evaluated. Moreover, the NHS Outcomes Framework<sup>2</sup> reaffirms the need to gather patient data to monitor service delivery and inform service improvement efforts.

However, gathering information from people at the end of life is problematic for several important logistical and ethical reasons. Firstly, as it becomes clear that death is approaching, people often become more frail and their level of consciousness decreases rendering them too ill to participate in interviews or questionnaire surveys. In addition, people dying from causes other than cancer have less predictable dying trajectories and so identification of the last stage of illness can be difficult.

Given these complexities it is often necessary to seek proxy reports about care provided at the end of life, particularly to capture events that occurred in the last few days and hours. Bereaved relatives or friends who were close to the deceased provide proxy reports that are valid and easily obtainable<sup>3-5</sup>. They also provide information on the adequacy of support received by carers and are the only way to gather information on the quality of end of life care given to those who die suddenly.

Although there is a paucity of evidence regarding the reliability of proxy responses, what limited evidence there is shows that while there is less agreement between patient and proxy for subjective symptoms such as pain, there is a good level of agreement on service use and evaluations of care quality<sup>6</sup>. Despite some weaknesses, pre-bereavement surveys are the only practical way of collecting representative data to reflect experience at this critical time.

## **1.1. 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.

Development of the original VOICES questionnaire was informed by a population based face-to-face interview survey of more than 3000 bereaved relatives in the UK<sup>7</sup>. Because of the costs associated with interview surveys and the research skills required to conduct them, VOICES was designed as a postal questionnaire<sup>8</sup>. This change in mode of administration had little effect on the rate and nature of response: an RCT comparing the type of responses, response rate and response bias from face-to-face interviews and postal questionnaires found very few differences<sup>8</sup>. In addition to the methodological and logistical advantages of self-completion postal questionnaires, there is some evidence to suggest that respondents prefer to complete sensitive questions themselves rather than being asked face-to-face by an interviewer<sup>9</sup>.

The VOICES questionnaire has subsequently been used successfully in at least thirteen surveys with over 4000 respondents<sup>10-13</sup> and further versions have been adapted for, and used successfully in, specific populations such as patients dying from stroke<sup>14</sup>, chronic heart disease, obstructive pulmonary disease (COPD)<sup>15</sup> and dying in a hospice.

The standard VOICES is a 144-item questionnaire, last revised in 2004. Since then there have been rapid developments to end of life care services necessitating revisions to the 2004 version.

## **1.2. Methods of Recruitment and Response rates**

Historically, the sample for a VOICES survey was identified by a variety of methods such as via healthcare records<sup>16</sup> which involved researchers sampling deaths from health authorities. However, changes in data protection meant that researchers could not directly approach people to take part in post-bereavement research or have access to their identifiable data. Henceforth, all population-based surveys of this sort have had to be conducted by The Office for National Statistics (ONS) using death certificates. This has had an adverse impact on response rates which have dropped from as high as 70% when using healthcare records to as low as 35% via ONS.

There is debate and conflicting opinion among Local Research Ethics Committees (LRECs) as to which is the most appropriate method of recruitment to post-bereavement surveys. In some VOICES surveys,

LRECs approved a recruitment protocol in which informants were sent an initial letter telling them about the survey and given the opportunity to opt in or opt out of receiving the questionnaire. This approval was based on the need to reduce the possibility of distress to bereaved respondents whilst still maintaining the representativeness of the sample. However, in other VOICES surveys LRECs have asked that informants are supplied a copy of the questionnaire with the initial invitation so that they may make an informed decision about participation. This inconsistency is unsurprising given that there is no evidence to support either approach.

Methods of recruitment to post-bereavement surveys can have an impact on response rate. For instance, in one VOICES survey<sup>17</sup> where the informants were required to 'opt in' by requesting a copy of the questionnaire from ONS, the response rate was 37%. This was considerably lower than that achieved in a study carried out in London in the following year (48%), which did not require participants to opt in. It is therefore important to determine the impact of recruitment approach on response rate in order to inform the planning of a national survey of end of life care.

As is often the case in population surveys, previous VOICES surveys have achieved a very low response from members of black and minority ethnic (BME) groups. An attempt to address this issue in a previous VOICES survey by providing translated versions of the questionnaire did not significantly increase response in BME populations<sup>11</sup>. A further focus of this current project was therefore to develop methods of increasing response in BME groups.

This piece of work was commissioned from the developers of VOICES to update the questionnaire, ascertain the appropriate recruitment approach, determine the required sample sizes to be able to make comparisons on care quality between care providers and develop methods of increasing response ahead of a national end of life care survey. This Final Report contains the details and outcomes of this project and describes end of life care in two PCTs.

After this survey commenced, a decision was made by the Department of Health to include surveys of bereaved relatives in Domain 4 of the NHS Outcomes Framework<sup>2</sup>. As a result of this decision, VOICES will be used to monitor care quality as part of the NHS Outcomes Framework.

## **2. Aims and Objectives**

- To adapt and test VOICES specifically for use as a measure of the quality of end of life care that reflects key aspects of the End of Life Strategy
- To investigate whether recruitment strategy can impact upon response rate in VOICES surveys
- To develop methods of maximising response rates in members of black and minority ethnic groups
- To produce guidance for the planning and execution of future VOICES surveys at both the national and local level

This Final Report outlines the processes involved in the re-development of VOICES, the survey methods, methods used to increase response (overall and in BME populations), required sample sizes for future VOICES surveys, results of the trial of recruitment approach, a detailed synopsis of the survey results (to include quantitative and qualitative data), and a series of recommendations that can be used to plan a national end of life survey using VOICES.

A Toolkit for the planning of locally-led VOICES surveys has been published separately.

### **3. Re-development of VOICES**

Over the last decade there have been six versions of VOICES, adapted for specific patient groups (heart failure, stroke) and for different care settings (hospice). The last version (DH VOICES) had 144 items (see Appendix A). In order to develop a more contemporary and shorter version that meets the requirements of the DH End of Life Care Strategy (thus reflecting changes in care planning and delivery priorities), a number of different procedures were employed:

- Addition of new questions to reflect the focus of the Strategy
- Gathering the views of professionals, patients and relatives
- Analysis of existing VOICES datasets
- Input from other experts and surveys
- Consultation with the Project Steering Group
- Gathering the views of specialist palliative care professionals and survey researchers

These methods were employed to refine the questionnaire ahead of the survey. The resulting prototype version of VOICES–Short Form formed the questionnaire that was used and tested in the survey. Details of the specific focus of the methods used to develop VOICES–Short Form can be found in Appendix B. The prototype version of VOICES–Short Form can be found in Appendix C.

The survey was then used to inform further refinement of the questionnaire and revisions were made to VOICES–SF after survey data collection took place. The methods employed to make these final revisions are detailed below.

#### **3.1 The Cognitive Interviews**

Given the timeline it was not possible to pre-test VOICES–SF prior to the survey. However, to better understand response problems and improve quality of data collected, cognitive interviews were undertaken with ten participants identified through the main survey (main survey methods described in Section 4). These participants responded to an invitation to take part in the interviews.

Two-hundred informants were invited to take part in the cognitive interviews. An invitation was issued to every seventh informant identified by the sampling strata (described in Section 4). Informants interested in taking part in these interviews returned a reply slip and were then sent an information sheet providing further material on what the interviews would involve. Those who wished to take part in the interviews contacted the research team directly to arrange an interview. Reminder letters were issued two weeks after the information sheets were posted if the informant had not contacted the

research team.

Interviews were conducted using 'Read aloud, think aloud' and verbal probing techniques to explore how the participants interpret and comprehend each question, retrieve relevant information, and to ascertain whether the response options were appropriate. In addition to these procedures, the participants were asked to comment on the completeness of the questionnaire, whether particular questions were markedly absent or whether the wording could be adapted to increase sensitivity.

### **3.1.1 Cognitive interview findings**

The results of the interviews indicated that certain words needed further clarification such as what is meant by 'Rapid Discharge Scheme'. In addition, respondents recommended adding other response options, such as 'lifeline', 'rapid response team' and 'domestic help' to the 'help from services question'. More comments boxes were encouraged and respondents asked that it be possible to incorporate lack of knowledge about the services available to the questions on health and social care.

Most participants indicated a need for the questions to account for a patients' inability to be involved in their own care for reasons such as cognition and level of consciousness and two respondents felt the questionnaire should account for a lack of choice about which GP they could see in a care home. It became apparent that certain questions were particularly valued by respondents such as continuity between care settings and being able to see the GP they preferred to see. However, a few new questions were suggested: discussing worries and fears with staff in the hospital, whether relatives were informed that death was imminent, whether they had sufficient warning to enable them to see their relative before they died and whether the healthcare staff were honest and upfront about prognosis.

## **3.2. Final revisions to VOICES-SF**

Using the themes and recommendations that arose from the cognitive interviews and the qualitative comments included in the returned questionnaires, the prototype VOICES-SF was then further revised. In addition, frequencies for each questionnaire item from the unweighted dataset were used to calculate maximum endorsement frequencies in order to identify redundant questions or response options. The final changes are summarised below:

### **Changes arising from the cognitive interviews:**

1. Given that all participants in the cognitive interviews expressed confusion over the term 'Rapid Discharge Scheme' and that no questionnaire respondents ticked the box indicating that their relative had used the service (as a response option in Question 3 – 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?), 'Rapid Discharge Scheme' was removed.

2. In the same question (Question 3), 'Meals-on-wheels' was changed to 'Meals-on-wheels or other home delivered meals'.
3. 'Does not apply' and 'Don't know' were added to Question 35 to align with Question 36.
4. Question 40 (Where did he die?) was rearranged to improve clarity.
5. Whether respondents were given sufficient warning of their relative's impending death to allow them to visit before they died was an issue raised by both the cognitive interviews and the qualitative comments from completed questionnaires and so a new question was added to cover this domain (Were you contacted soon enough to give you time to be with him before he died?).
6. Given the concern over patients being unable to make decisions as a result of cognitive impairments or reduced consciousness, a comments box was added after Question 48 (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?).

#### **Changes arising from analysis of the qualitative data:**

1. 'Rapid Response Team' and its definition was added to Question 3 (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?)
2. 'Lifeline pendant' and 'Something else' was added to Question 8 (The last time this happened[out-of-hours services were contacted], who was contacted on his behalf?).
3. The comments pages at the end of the questionnaire were re-arranged so that 'What was good about the care?' and 'What was bad about the care?' now precede 'Please use the space below if there is anything more you would like to say about the care provided'.

#### **Changes arising from the quantitative analysis and analysis of maximum endorsement frequencies:**

1. The response option, 'One year or more' was added to Question 1 (How long had he been ill before he died?) in order to allow differentiation between the 55% of respondents who indicated their relative had been ill for over six months.
2. The response options for Question 12 (How often did the community nurses visit at the most frequent time?) were amended to ensure that they were all mutually exclusive.
3. The response option 'The GP did not visit in the last three months; they were not wanted' was removed from Question 18 (Overall if the GP visited him at home, how easy or difficult was it to get him/her to visit?) because it was used by fewer than 2% of respondents and another response option provided a similar answer (Does not apply – the GP did not need to visit).
4. There was duplication of the question about decisions at the end of life. In the 'last Two Days' a question was worded as 'During these last two days, were there any decisions made about his

care or treatment that he would not have wanted?', whilst a similar question was included in the 'Circumstances Surrounding His Death' section, 'Were any decisions made about his care that he would not have wanted?'. The decision was made to remove the question from the 'Last two days' section.

5. Because of the way that response options were arranged (not entirely mutually exclusive), the data yielded from the question on bereavement support did not allow detailed understanding of the reasons why bereavement services were not accessed. Therefore, the response option 'no' was removed from the question on bereavement services, thus leaving the following response options as: 'Yes', 'No, but I would have liked to', 'No, but I did not want to anyway', and 'Not sure'.
6. The ethnicity and religion questions in the demographics section were replaced with the questions used in the 2011 Census.

### **3.3. VOICES-Short Form: A contemporary measure of the quality of end of life care**

Following all of these changes, the final version, named VOICES-Short Form (VOICES-SF), contains 58 questions and covers care at home, from community nurses, out-of-hours services, GPs, hospitals, hospices, care received in the last two days in any setting and circumstances surrounding the death. This final version is located in Appendix D.

## **4. Survey Methods**

### **4.1. Research Questions**

- What is the effect of recruitment method on response rate in a VOICES survey of bereaved relatives?
- Can response rate be increased through multi-mode data collection (Paper and pencil, on-line) and study promotion?
- Can response in BME groups be increased through promotion and recruitment of a boost sample?
- What sample sizes are required to explore quality of services between PCTs based on place of death and cause of death?

### **4.2. Design**

A comparative trial of recruitment methods embedded within a questionnaire-based, cross-sectional survey of bereaved relatives.

### **4.3. Setting**

Two PCTs within the South Central SHA were invited to take part in the survey: Berkshire East PCT, a culturally and economically diverse population encompassing Windsor, Slough and Reading; and the Isle of Wight PCT, a smaller, less culturally diverse PCT with an older population. Given that the key aim of the trial was to inform the planning of the national survey, collaboration with PCTs was pivotal.

Focusing recruitment within two specific PCTs made it possible to ascertain whether a sampling frame could be developed that could facilitate between-PCT analysis of the key comparisons of interest (sex, cause of death, place of death) whilst still maintaining statistical power.

### **4.4. Eligibility criteria**

All deaths registered in Berkshire East and the Isle of Wight PCTs between 1<sup>st</sup> October 2009 and 1<sup>st</sup> April 2010 were eligible. However, the following deaths were excluded:

- Deaths registered less than 6 months before and more than 12 months after the sample was extracted. This approach has been used in many surveys using VOICES 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.
- Deaths registered by a Coroner. These were excluded for ethical reasons and because, in the case of accidental deaths and suicides, it is unlikely that any health or social services would

have been involved in end of life care. This is also current ONS protocol.

- Deaths where the informant lives overseas (not including Channel Islands).
- Deaths classified as occurring 'elsewhere'.

#### **4.5. Sampling**

Given that the study set out to ascertain whether it would be possible to compare care experiences based on place of death and cause of death between PCTs, the sampling strategy needed to ensure that deaths included in the sample were representative of all deaths in the two PCTs. Using all deaths registered in Berkshire East PCT and the Isle of Wight PCT between 1<sup>st</sup> October 2009 and 1<sup>st</sup> April 2010 as the sample frame, a self-weighting, proportionally allocated stratified sample design was employed, using the following strata:

- 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
  - cancer related
  - cardiovascular disease
  - other

The sample frame was then created by sorting deaths according to the variables that define the strata. Sample selection was carried out automatically using systematic sampling in each stratum after sorting by age at death using Statistical Analysis Software code.

#### **4.6. Survey Management**

Given data protection restrictions which meant that research staff could not access personal data on the informant or decedent, data collection was conducted by the Office for National Statistics (ONS) who selected a sample from the pre-defined sample frame described above under the guidance of the project researchers at the University of Southampton. ONS identified potential respondents through death certificates and contacted the informant at their home address to invite them to take part in the survey.

All deaths (and their informants) were assigned a unique identification number to reflect PCT affiliation, trial group assignment, sex and strata. Using these IDs, ONS were able to keep a log of responses to ensure participants were not sent reminder letters if they had already completed the questionnaire or

had declined to participate by returning the 'opt out slip' (see Appendix E).

Two reminders were scheduled, three weeks after the initial mail-out and then another, two weeks after that. At the second reminder, the 'single posting' group received a second copy of the questionnaire.

Following concern that difficulties in completing the questionnaire may be a barrier for participation, a telephone information and helpline provided by the researchers for assistance in completing the questionnaire was made available. Moreover, previous surveys have achieved a very low response in older populations and although there are many reasons for this, poor vision may be contributory. The invitation letter therefore featured a title in large print and a telephone number to call to request large print versions of the information sheet and questionnaire.

#### **4.7. The Trial**

To answer the key question about the most appropriate and sensitive method of recruiting informants to post-bereavement surveys, a trial of recruitment approach was nested within the survey. The trial was designed to ascertain whether providing the questionnaire with the initial survey invitation was associated with a higher response rate than asking invited participants to opt in to the survey by requesting a copy of the questionnaire. A further aim was to establish whether there was a difference in the number of complaints between recruitment methods.

Potential participants were assigned to one of two groups using the strata, thus ensuring that both groups were equal with respect to the stratifying variables. The sample data were ordered according to the strata and the odd numbered records were assigned to the 'opt in' group in which informants had to request a copy of the questionnaire. The even number records were assigned to the 'single posting group' in which informants were sent a copy of the questionnaire. The study groups were as follows:

##### Group 1 – the 'single posting' group

Potential participants in the 'single posting' group received a letter of invitation from ONS introducing the survey, a copy of the VOICES questionnaire, a participant information sheet and a reply slip to request no further contact from ONS (respondents also had the opportunity to telephone ONS to make this request).

##### Group 2 – the 'opt in' group

Those assigned to the 'opt in' group received a letter of invitation from ONS introducing the survey, the information sheet and a reply slip *to request the questionnaire* or to request no further contact or reminder letters from ONS. (All study documentation is found in Appendix E)

Both groups had the opportunity to complete the questionnaire online using the same method. This meant that those in the 'opt in' group could avoid having to request the questionnaire by completing online.

#### **4.8. Online Version of the questionnaire**

A key aim of the survey was to explore methods of increasing response among informants. Surveys are increasingly conducted online and there is growing evidence to suggest that people like to engage in research using that medium<sup>18</sup>. Therefore, an online version of the questionnaire was designed and constructed using iSurvey, a University of Southampton software package. The online version of the questionnaire was hosted on the survey website at [www.southampton.ac.uk/voices](http://www.southampton.ac.uk/voices). Access to the survey was regulated with a password.

The letter of invitation from the University of Southampton directed participants to the study website and provided them with a unique identifier code and log-in. Upon completion, data were stored by the online survey software and downloaded at the end of data collection.

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

A combination of the following methods was employed to attempt to increase participation in members of minority ethnic groups:

- Interpretation and translation
- Awareness-raising and advertising
- A BME boost sample

Details of the specific focus of these activities can be found in Appendix G.

## **6. Ethical Considerations and Procedures**

Given that the survey was conducted outside NHS premises and did not involve NHS patients or staff, it was not necessary to seek NHS ethical approval. Ethical approval was therefore sought from the University of Southampton, Faculty of Health Sciences Ethics Committee. Research Governance, insurance and Sponsorship were provided by the University of Southampton. In addition, the project protocol was reviewed by the Head of Health Analysis, at the Office for National Statistics.

There is the potential for distress in all research with bereaved people. Therefore, it was clear in the letter of invitation, information sheet and on the front page of the questionnaire that participation was voluntary and respondents could stop completing the questionnaire at any time. All informants were provided with sufficient information to be able to make an informed decision about participation. In addition, respondents could contact the research team with any questions about the survey.

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

Given the sensitive nature of the survey, the vulnerability of informants and the need to ensure that informants were given support to complete the questionnaire, a series of support structures were put in place. These were designed to achieve the following:

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

## **7.1. Responding to emotional distress**

A mechanism was developed in order to address the fact that the survey had the potential to provoke distress and raise issues that a respondent may need help to explore. This involved collaboration with Cruse Bereavement Care. Cruse contributed to the development of all documentation delivered to participants, thus ensuring that the wording of the questionnaire and information sheet was appropriate for the population.

Cruse agreed to provide telephone advice and support for respondents in both PCTs and also offered to arrange face-to-face meetings with those who needed it. The Cruse telephone number was provided on the Information Sheet and Invitation Letter as well as on the front page of the questionnaire itself. In addition, the Cruse logo was included on all paperwork. Although experience in these types of surveys suggests that demand for this support is limited, provision of emotional support in response to participants needs was considered essential. This support was also available for participants who took part in the cognitive interviews.

Because non-English speakers could not make use of the Cruse Bereavement Care telephone support service, interpreters could direct callers to a support line that was able to offer help in a number of Asian languages. This was provided by the Slough Asian Carers Support Service, thus providing support for the predominant languages in the data collection sites.

## **7.2. Responding to complaints**

A framework for dealing with complaints about the conduct of the research or the care received by the decedent was established.

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

Procedures were put in place to deal with complaints about the care provided by health and social services. Where negative comments were detailed on the questionnaire, no direct action could be taken unless the participant explicitly requested that this should happen and provided their contact details. Complaints expressed in writing or verbally and passed to the research team were discussed with, and handled by, the SHA.

### **Complaints about the research**

The information sheet directed all respondents to the Research and Enterprise Office in the Faculty of Health Sciences should they have complaints about the research.

## **8. Promotional Strategy**

Increasing response rates and reducing response bias is desirable in population surveys. Various methods of increasing response rates through communicating about the survey to different audiences were developed. The following four approaches were taken:

- a. Study website
- b. Press releases
- c. Local awareness-raising
- d. Alerting health and social care staff

### **a. Study website**

The study website was an important source of information about the survey. The website was used as a single information point and held information on the survey itself, the VOICES questionnaire, key collaborators such as ONS and publications from previous VOICES surveys. The website was aimed at respondents, staff and other interested parties.

Moreover, the website was used to host the online version of the survey.

### **b. Press releases**

Three press releases (Appendix H) were issued to coincide with each of the postings (initial mail-out, and both reminders). These were written in collaboration with the SHA and the University of Southampton Communications Department. The SHA sent out the press releases to newspapers and radio stations (see Appendix I for a full list of organisations approached) in an attempt to broadcast the survey to a wide audience and reaffirm its importance to those sent invitation letters.

### **c. Local awareness-raising**

Within each PCT, further awareness-raising was achieved through local voluntary organisations. For instance, Berkshire LINKs (Local Involvement Network) agreed to circulate information about the survey to all members of their mailing lists and also published information about the survey on their website and the e-bulletin. Moreover, the local branches of Age Concern and the Inequalities Networks cascaded information to members.

### **d. 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 was particularly important that staff working in the data collection sites were aware of the survey. To achieve this, meetings were held with Specialist Palliative

Care staff, commissioners and PCT representatives for end of life care. A letter was drafted and cascaded to key service managers by the PCT, and specialist palliative care providers (such as hospices) were contacted directly by the research team.

In addition, the SHA End of Life Care Newsletter published updates on the survey to ensure a greater reach of professionals.

## 9. Findings

For the time period of interest (1<sup>st</sup> October 2009 to 1<sup>st</sup> April 2010 inclusive), 2272 deaths were registered within the boundaries of Berkshire East PCT and the Isle of Wight PCT. A final sample of 1446 deaths was drawn after excluding:

- a. 788 coroner-registered deaths
- b. 13 deaths in persons aged under 18 years
- c. 8 deaths classified as occurring 'elsewhere'
- d. 17 deaths where the informant lived overseas (not including Channel Islands)

A further 24 deaths were excluded after the sample was drawn and questionnaires were mailed out because the informant had changed address. This figure relating to undelivered questionnaires is likely to be an underestimate because it was reliant upon questionnaires being returned to ONS. The final sample size was therefore 1422 deaths.

Demographic characteristics of the final sample, showing characteristics of both PCTs and excluded coroner-registered deaths are presented in Table 9.1. In addition, and as a means of comparing with data at the national level, characteristics of all deaths in England over the same time period (1<sup>st</sup> October 2009 to 1<sup>st</sup> April 2010 inclusive) are also presented.

There are notable differences between the PCTs on these demographic and health service factors (Table 9.1). For instance, an older population in the Isle of Wight, a higher proportion of males in Berkshire East and a considerably higher proportion of deaths from deprived areas in Berkshire East. Regarding health and services, Berkshire shows a higher proportion of home deaths and a higher proportion of hospital deaths, highlighting a move towards more deaths in care homes in the Isle of Wight. Deaths from cardiovascular diseases were similar across the PCTs although a higher proportion of deaths were attributable to 'other causes' in the Isle of Wight. Further discussion of the effect of excluding coroner-registered deaths from the final sample can be found in the following section (Section 9.1).

There are also some notable differences between the sample and England as a whole. For instance, the sample has a higher proportion of the oldest-old (90+ years) than is found in England. There is also a lower incidence of CVD deaths in the sample compared to England and a considerably higher proportion of deaths from other causes in the Isle of Wight. Interestingly, the proportion of people dying at home was markedly lower in the sample than in England although this may be partly attributed to the exclusion of coroner-registered deaths from these figures (Table 9.1).

**Table 9.1: Demographic characteristics of the sample, excluded coroner-registered deaths and deaths in England – frequencies (%)**

	Sample (n=1422)	IOW (n=557)	Berkshire (n=865)	Excluded Coroner- registered (n=788)	England (n=241,770)
<b>Sex</b>					
Male	43.4 (617)	40.8 (227)	45.1 (390)	55.8 (440)	(47.7) 115,227
Female	56.6 (805)	59.2 (330)	54.9 (475)	44.2 (348)	(52.3) 126,543
<b>Age group</b>					
18-19	0 (0)	0 (0)	0 (0)	1 (8)	0.1 (222)
20-29	0.2 (3)	0 (0)	0.3 (3)	0.8 (6)	0.6 (1414)
30-39	0.7 (10)	0.4 (2)	0.9 (8)	2.4(19)	1.1 (2714)
40-49	1.7 (24)	0.5 (3)	2.4 (21)	5.8 (46)	2.9 (6898)
50-59	5.9 (84)	5.0 (28)	6.5 (56)	8.1 (64)	5.7 (13,874)
60-69	9.4 (133)	7.7 (43)	10.4 (90)	11.0 (87)	11.9 (28,856)
70-79	20.5 (292)	19.4 (108)	21.3 (184)	20.3 (160)	22.5 (54,422)
80-89	37.1 (528)	37.9 (211)	36.6 (317)	36.5 (288)	37.3 (90,299)
90+	24.5 (348)	29.1 (162)	21.5 (186)	14.0 (110)	17.8 (43,071)
<b>PCT</b>					
Berkshire	60.8 (865)			57.9 (456)	
Isle of Wight	39.2 (557)			42.1 (332)	
<b>Cause of death</b>					
CVD	24.9 (354)	25.3 (141)	24.6 (213)	51.2 (400)	32.9 (79,658)
Cancer	34.1 (485)	30.5 (170)	36.4 (315)	12.0 (94)	27.8 (67,133)
Other	41.0 (583)	44.2 (246)	39.0 (337)	36.8 (288)	39.3 (94,979)
<b>Place of death</b>					
Home	13.7 (195)	12.9 (72)	14.2 (123)	32.2 (254)	20.5 (49,668)
Hospital	51.0 (725)	47.4 (264)	53.3 (461)	53.7 (423)	54.2 (130,974)
Care home/hospice	35.3 (502)	39.7 (221)	32.5 (281)	14.1 (111)	25.0 (60,417)
<b>Deprivation</b>					
1	26.4 (375)	2.5 (14)	41.7 (361)	21.7 (171)	18.0 (43,556)
2	20.7 (294)	17.4 (97)	22.8 (197)	19.4 (153)	20.5 (49,463)
3	26.1 (371)	42.4 (236)	15.6 (135)	26.6 (210)	21.0 (50,721)
4	23.3 (331)	31.1 (173)	18.3 (158)	26.9 (212)	20.4 (49,339)
5	3.6 (51)	6.6 (37)	1.6 (14)	5.3 (42)	20.1 (48,691)

### 9.1. Should Coroner-registered deaths be excluded from VOICES surveys?

As detailed in Section 4.4, all deaths registered by a Coroner were excluded from the sample. This decision was based on the need to exclude suspicious deaths, accidents and suicides, the difficulty in identifying the informant in these cases and current practice at ONS. However, on closer inspection, Coroner-registered deaths form a considerable proportion of all deaths and therefore their characteristics require closer examination. For instance, it is important to ascertain whether Coroner-registered deaths constitute a discrete group with characteristics that are statistically significantly different to deaths registered by informants. If this were the case, the incorporation of these deaths, where appropriate, into a VOICES sample would be necessary.

Of the 2272 deaths that occurred in the data collection sites and over the time period of interest, 789 were registered by a Coroner. Inspection of the causes of these deaths reveals that only a small proportion (n=50, 6.3%) were registered as suspicious deaths, accidents or suicides. This is based on the following ICD-10 codes:

- a. S00-T98 – Injury, poisoning and certain other consequences of external causes
- b. V01-Y98 – External causes of morbidity and mortality

A summary of the codes assigned to these deaths is provided in Table 9.2.

**Table 9.2: Cause of death for Coroner-registered deaths (S00-Y89) excluded from the sample**

Frequency	Broad cause of death based on ICD-10 codes
3	Transport accident
7	Fall
1	Inhalation of gastric contents
2	Inhalation of smoke during a fire
4	Accidental poisoning from drugs/alcohol
19	Exposure to unspecified factor
9	Intentional self-harm
4	Poisoning/hanging/contact with a moving object, undetermined intent
1	Complications from surgery

Comparison of the demographic data for the Coroner-registered deaths that could be included in future VOICES surveys (those coded A000-R99) and the VOICES sample (including non-responders) shows considerable differences. In fact, these differences are statistically different on all parameters (Age at death, Sex, Cause of death, Place of death and PCT). For instance, Coroner-registered deaths were significantly more likely to take place at home than deaths in the VOICES sample (32.6% compared to 13.7% - diff=18.9, 95% CI=18.84:18.96), more likely to be caused by CVD (54.7% compared to 24.9%, diff=29.8, 95% CI=29.72:29.88), or 'Other causes' (32.4 compared to 41.0, diff=-8.6, 95% CI=-8.68:-8.52), less likely to be caused by Cancer (12.9% compared to 34.1%, diff=-21.2, 95% CI=-21.27:-21.12), more likely to be male (56.4 compared to 43.4, diff=13, 95% CI=12.96-13.04) and more likely to be deaths in younger people.

Given that it is possible to exclude only those Coroner-registered deaths (using ICD-10 codes) where it would be judged unethical to contact the relatives or unlikely that any health or social care services would have been instigated, and the statistical differences in the characteristics between Coroner-registered deaths and deaths registered by informants, it could be judged to be more appropriate in

future to exclude only those coded under ICD-10 codes S000-Z99. This would ensure greater representativeness of the sample and increase the size of the target population, whilst upholding ethical practice and protecting the most vulnerable.

Death certificates completed following coroner-registration still detail the name and address of an informant, thus facilitating recruitment of the appropriate bereaved relative. Moreover, ONS are happy to take this approach.

## **9.2. Assessment of Non-Response Bias**

Given that the response rate was reasonably low (as is usually the case in this type of research), it is necessary to explore the degree of non-response bias in the sample because it is possible that the responders were different to the non-responders on parameters that may affect the way that they completed the questionnaire. 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. To calculate this, responders were compared with non-responders and differences between groups were assessed using Chi Square.

Although there were patterns of difference for most variables, statistically significant differences were only noted for four of the eight variables: trial study group played a role with a significantly higher response in the 'single posting' group, ( $p < .001$ ), female informants were more likely to respond than male informants ( $p < .001$ ) and informants who registered the death of someone who died of cancer were more likely to respond than for decedents with cardiovascular or other causes of death ( $p < .05$ ). Place of death was also associated with response: informants were significantly more likely to respond if their relative/friend died at home rather than in hospital or in a hospice or care home ( $p < .001$ ). There were no statistically significant differences in deprivation score, PCT, decedent sex and decedent age between the responders and non-responders (Table 9.3).

**Table 9.3: Characteristics of Responders and non-responders**

	<b>Responders</b>	<b>Non-responders</b>	<b><i>P</i>(<math>\chi^2</math>)</b>
Deceased sex			
Male	178 (28.8)	440 (71.2)	<i>p</i> =.13 (2.25)
Female	262 (32.5)	544 (67.5)	
Deceased age			
18–59	37 (30.6)	84 (69.4)	<i>p</i> =.83 (1.51)
60–69	37 (27.8)	96 (72.2)	
70–79	85 (29.1)	207 (70.9)	
80–89	166 (31.4)	362 (68.6)	
90+	113 (32.5)	235 (67.5)	
Informant sex			
Male	164 (25.5)	479 (74.5)	<i>p</i> <.001 (16.51)
Female	273 (35.5)	495 (64.5)	
PCT			
Berkshire East	256 (32.9)	609 (70.4)	<i>p</i> =.19 (1.75)
Isle of Wight	184 (29.6)	375 (67.1)	
Trial group			
‘Opt in’ Group	173 (24.4)*	535 (75.6)*	<i>p</i> <.001 (25.36)
‘Single posting’ Group	261 (36.8)*	449 (63.2)*	
Deprivation score (ID2007 Quintile)			
1	120 (32.0)	255 (68.0)	<i>p</i> =.062 (8.97)
2	97 (33.0)	197 (67.0)	
3	126 (34.0)	245 (66.0)	
4	82 (28.8)	249 (75.2)	
5	13 (25.5)	38 (74.5)	
Place of Death			
Home	76 (39.0)	119 (61.0)	<i>p</i> <.001 (16.23)
Hospital	191 (26.3)	536 (73.7)	
Care Home/Hospice	173 (34.5)	329 (65.5)	
Cause of Death			
CVD	106 (29.9)	248 (70.1)	<i>p</i> <.05 (7.41)
Cancer	171 (35.3)	314 (64.7)	
Other causes	161 (27.6)	422 (72.4)	

\*Note this is based on dataset excluding anonymous returns (n=33)

Given that non-response bias was evident for both place of death and cause of death, variables which reflect care received, and the response rate is low, it was necessary to apply sample weights that would address the under-representation of particular groups by increasing the influence that certain responders have in the analysis. This is the first time that weighted data have been used in a VOICES survey. The methods used to weight the data are further discussed in Section 9.9.

### 9.3. The Comparative Trial: Which is the best method of recruitment to a VOICES survey?

After removal of the 24 cases where the informant had changed address, a final sample of 1422 was drawn. Of these, 473 responded by either completing a paper version of the questionnaire or completing online, thus bringing the overall response rate for the survey to 33%.

The response rate was higher in the Isle of Wight PCT (35.6%, n=199/559) than Berkshire East PCT (31.7%, n=274/865). Response rates are summarised below:

- Overall response rate = 33% (n= 473/1424)
  - Opt in Group = 26.4% (n=188/712)
  - Single posting Group = 40.0% (285/712) (p<.001)
- Berkshire East Response rate = 31.7% (n=274/865)
  - Opt in Group = 23.7% (n=66/278)
  - Single posting Group = 35.5% (n=153/431)
- Isle of Wight Response rate = 35.6% (n=199/599)
  - Opt in Group = 27.9% (n=121/434)
  - Single posting Group = 47.3% (n=133/281)

188 members of the 'opt in' group returned either a paper version of the questionnaire or completed online, giving a response rate of 26.4% (n=188/712). Response was considerably higher in the single posting group with 285 informants returning paper or online questionnaires (n=285/712). The response rate for the 'single posting' group was therefore 40.0% which was statistically significantly higher than in the 'opt in' group ( $\chi^2$  29.7860, p<.001).

Given that there were no formal complaints about the research in either group, and only two respondents contacted Cruse for emotional support, the 'Single posting' method can be recommended as the most appropriate recruitment method for future VOICES surveys.

### 9.4. Why do people choose to opt out of a VOICES Survey?

One hundred and sixty-eight participants formally opted out of the survey by returning the 'opt out' slip (both trial groups). Therefore, 781 of the sample did not complete the questionnaire or opted out. More than half of those who *formally* opted out did not give a reason. Where a reason(s) was given, these fell into the following categories:

- The questionnaire was too distressing (n=33)
- The informant registered the death in a professional capacity and did not know the decedent personally (n=13)
- Limited knowledge of the deceased's care or inability to recall the events leading up to the death (n=2)
- The deceased died suddenly (n=6)
- Disapproval of the survey – for instance, too much money is spent on research (n=3)
- Assumption that the deceased died of a condition that would not be included in the survey (n=4)
- The deceased received no care (n=4)
- Wrong recording of death registration (n=1)

Although some of these reasons are inevitable in this kind of research, others could potentially be minimised by slightly changing the wording of the study documentation (see Recommendations).

### **9.5. Does offering an online version increase response rate?**

Only 88 of all informants (12.4%) chose to participate using this medium. Interestingly, a large proportion of the online responders were assigned to the 'opt in' group, thereby bypassing the need to 'opt in' to the study by requesting a copy of the questionnaire: sixty-five (34.6%) of the 188 'opt in' group responders completed online compared to only 28 (9.8%) of the 'single posting' group.

Therefore, only 17.3% of informants assigned to the 'Opt in' Group completed a paper questionnaire. The addition of an online version of the questionnaire appears to considerably increase response using an 'opt in' method but if informants receive the questionnaire in the first instance, availability of an online version does not appear to impact that markedly on response rate.

Response rates for the online version of the questionnaire are summarised below:

- |   |
|---|
| <ul style="list-style-type: none"> <li>▪ 207 logged on</li> <li>▪ 88 responded online (12.4% of responders) <ul style="list-style-type: none"> <li>▪ 65 in 'Opt in' Group (34.6% of Group)</li> <li>▪ 28 in 'Single posting' Group (9.8% of Group)</li> </ul> </li> <li>▪ Only 17.3% of 'Opt in' Group completed a paper version</li> </ul> |
|---|

## 9.6. Did the BME Strategy improve response rate in the BME population?

Given that death certificates do not detail ethnicity, determining response rates by ethnic group was not possible. Ethnicity data are only available for those who completed the questionnaire. Thirty-four respondents did not complete the question about their ethnic group. Of the 439 who did complete this item, only 10 (2.3%) described themselves as belonging to a minority ethnic group (Table 9.1). In addition, there was only one call to the interpreting service.

**Table 9.4: Ethnicity in the sample**

<b>Ethnic Group</b>	<b>Frequency (%)</b>
White	429 (97.7)
Black Caribbean	1 (0.2)
Indian	6 (1.4)
Pakistani	1 (0.2)
Other	2 (0.5)
Total	439

Although ascertainment of the proportion of minority ethnic groups in the entire sample is not possible, 'place of birth', a variable that is collected during the death certification process, can provide an approximation, albeit underestimate, of the size of the BME sub-sample in our original sampling frame. Using 'place of birth', 88.5% of the sample were born in the UK and 2.7% in the Republic of Ireland. The remaining 8.8% were born outside of the British Isles (Table 9.2).

**Table 9.5: Place of birth in the sample**

<b>Country of Birth</b>	<b>Frequency (%)</b>
UK	1258 (88.5)
Ireland	39 (2.7)
Any other European country/ Australia/USA/Russia	47 (3.3)
India	29 (2.0)
Pakistan	15 (1.1)
Any other Asian country	4 (0.3)
Caribbean	6 (0.4)
Africa	15 (1.1)
China	5 (0.4)
Any other country	4 (0.3)
Total	1422

Estimating the true BME population size in the data collection sites is also problematic. Data are known to be unreliable and are not frequently updated. However, using the 2007 ONS Population Estimates by Broad Ethnic Group by sex for those aged over 16 in Berkshire East; 27,800 males and 27,600 females were classed as Not White (Table 9.3).

**Table 9.6: Ethnicity in Berkshire East - ONS 2007 data**

	White Population in Berkshire East	Non White Population in Berkshire East
Male	123,500	27,800
Female	128,500	27,600

Using these figures it is possible to explore the number of deaths in over 16 year olds in Slough, Bracknell Forest and Windsor and Maidenhead Unitary Authorities (these data were not available for Berkshire East PCT) by sex in order to provide an estimate of the number of expected deaths in minority ethnic groups. In these areas there were 1295 deaths in males and 1363 deaths among females (2008 data).

Using proportional allocation, and the population and death data above, there would have been an expected 293 deaths in the female non-white population and 238 deaths in the male non-White population. However, 34.7% of the sample was excluded as Coroner-registered deaths. Therefore, after applying the same proportion of Coroner-registered deaths to the expected number of Non-White deaths, the number of deaths in non-Whites in the VOICES sample (n=1422) can be estimated at 184. This method produces a higher estimate of deaths in non-whites compared to using Place of Birth alone (n=78) and places the *estimated* response rate for BME groups at 5.4% (compared to 12.8% if using Place of Birth as the measure of ethnicity).

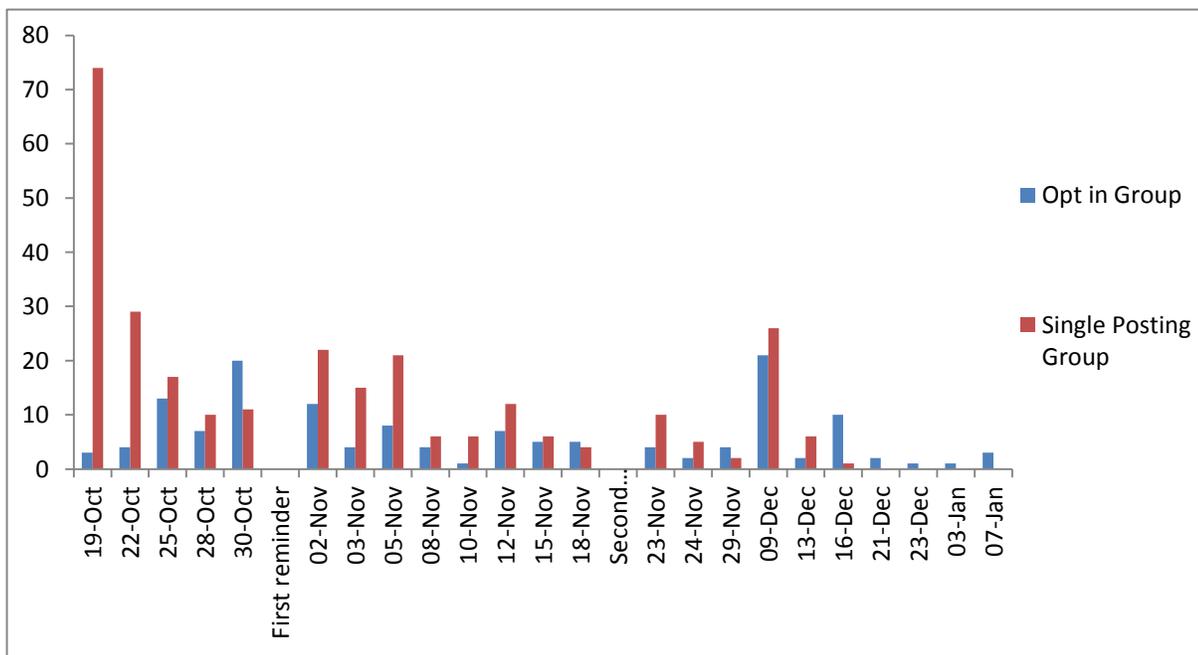
However, caution should be applied in interpreting these figures because data were collected at different time points in each dataset, employ different ethnicity classifications and age cut-offs (the ONS data included deaths in 16 year olds rather than the 18 years cut-off employed in the VOICES sample). In addition, these data do not take life expectancy or age structure across ethnic groups into account, both factors which limit the extent to which data can be extrapolated from other population groups.

Given that the response in BME groups is not significantly greater than the proportion of BME responders in previous VOICES surveys, the strategies developed on this occasion appeared to have had no effect.

## 9.7. Did media promotion have an effect on response?

Three press releases were issued to coincide with the initial mail-out of questionnaires and the two reminders. Analysis of the timing of this promotion on response indicates a considerable effect. One newspaper article was printed in the Isle of Wight local newspaper, alongside a radio interview with Isle of Wight Radio. Both of these news pieces resulted in a considerable number of telephone calls for further information about the survey and a noticeable increase in returned questionnaires. Four bereaved relatives requested a copy of the questionnaire after reading about the survey. In Berkshire East, four articles were published in local newspapers and were also associated with an increase in response in that site (See Figure 9.1).

**Figure 9.1: Response patterns over time by Trial Group**



Although a concerted effort was made to feature on local Asian radio and in local Asian newspapers, no articles were published.

As is also visible in Figure 1, both of the reminder letters had a positive impact on response with peaks in the number of returned questionnaires after each mail-out, thus illustrating the utility of a second reminder (this is the first time two reminders have been used in a VOICES survey). Note how the peaks are delayed in the 'opt in' group because those participants had to first request a copy of VOICES. However, the effect of the reminder letters on the response rate cannot be isolated from the effect of the press releases.

## **9.8. Comparing experiences of care at the end of life across PCTs**

Because of the degree of unit non-response bias in the sample (only 33% of the sample responded to the survey), sample weights were applied to all questionnaire data. Weights were constructed based on:

- Sex of the deceased
- PCT
- Place of death
- Cause of death

This ensured that underrepresented groups could be accounted for. For example, there was a lower response among respondents whose relative died in a hospital compared to relatives who died at home (see section 9.2). Therefore, greater weights were assigned to those who died in hospital, to increase their representation in the sample.

In addition, because there were a small number of anonymously returned questionnaires (where the front page and ID number were removed), there was an absence of place and cause of death data for these deaths. Imputational methods were therefore used to estimate the place and cause of death in these cases.

In the sections that follow, the findings from the questionnaire items are reported. All displayed data in these sections are weighted according to the aforementioned criteria. Because of the different sample sizes between population sub-groups, data are displayed as percentages with frequencies in parentheses (note that the survey weights mean that frequencies are presented as decimal fractions).

Data are presented for the whole sample, for each PCT and then within each PCT based on comparisons of place/cause of death. The questionnaire items are displayed in text boxes (with their precise wording and response categories) and organised according to the following End of Life Care Strategy expectations of VOICES:

9.8.2 Quality of care in different settings

9.8.3 Dignity and respect

9.8.4 Co-ordination of care

9.8.5 Relief of pain and suffering

9.8.6 Support in the last two days of life

9.8.7 Patient's needs and preferences

9.8.8 Support for carers

9.8.9 Preferred Priorities for Care

9.8.10 After-death support

Qualitative comments were analysed and coded under the above nine DH End of Life Care Strategy themes described above. 294 respondents provided written comments for the last three open questions. Selected quotations are inserted amongst the quantitative data, organised by End of Life Care Strategy theme. The following table (Table 9.7) presents the proportion of patients who received care in each care setting and the nature of the qualitative comments that each setting received.

**Table 9.7: Proportion receiving care in each care setting, including free text comments**

Care setting	Proportion receiving care	No. positive comments	No. negative comments
Hospital	72.4%	57	92
Hospice	15.7%	23	5
Care home	36.5%	51	32
Out-of-hours	22.8%	8	2
District nurses	52.9%	20	4
GP	71.5%	22	26
Macmillan nurses	22.4%	11	5
Hospice at home	3.5%	8	1
Marie Curie	8.8%	2	0
Social Services		4	12

The majority of decedents had been ill for six months or longer before they died (55.8%). 22.5% had been ill for more than one month, but less than six months, 8.7% for less than a month, 3.4% less than once a week, 1.5% less than 24 hours and 2.7% had not been ill at all and died suddenly.

### 9.8.1. Summary of findings from the survey

The main findings from responses to questionnaire items are summarised below. The next section (Section 9.8.2) provides the data and detail on these findings.

- VOICES-SF can detect differences between PCTs and care settings, and between place of death and cause of death within PCTs.
- More than half of respondents provided qualitative data and this mainly focused on issues pertaining to dignity and respect or overall quality in individual care settings.
- Among all care settings, hospice care was the most consistently rated as 'excellent', and hospital care rated the poorest.
- District nurses and community staff received very good ratings for dignity and respect but this was not the case for hospital staff, particularly hospital nurses.
- Care was not well co-ordinated between care settings – either between community services or between acute and community settings.
  - CVD patients experienced particularly poor co-ordination from community services, in both PCTs.
- Although pain relief was excellent in hospices, it was poorly controlled in the home setting.
- Care provided in the last two days varied considerably between those who died of different conditions and those who died in different care settings. For instance:
  - Those who died in a hospice were more likely to have their personal care needs met than those who died in a hospital.
  - Cancer patients were more likely to have their nursing needs met than those who died of CVD.
  - Privacy in hospital in the last two days was poorly rated.
  - Pain and other symptoms were more poorly controlled among those who died in hospital than among those who died in other care settings.
  - Support to allow the patient to stay where they wished in the last two days was better rated in the Isle of Wight than in Berkshire East.
- The process of breaking bad news was more poorly rated among CVD patients than those who died of other conditions.
- The majority of patients died in hospital (47.7%).
- The minority of patients said where they would like to die (35.4%).
  - This was highest among cancer patients (47%) and those who died at home (78%).
- The majority expressed a wish to die at home and almost half (44.6%) died where they wanted.
- There was a record of preferred place of death in only 36.1% of cases (although this is likely to be an underestimate).
- Half of carers received enough support in looking after their relative/friend.

- Sixty percent received sufficient support at the time of the death but the proportion was smaller among respondents whose relative died in hospital than elsewhere.
- A very small proportion of respondents had spoken to a bereavement/alternative service.

### 9.8.2. Quality of care in different settings

Quality of care was assessed across care settings using a general question of overall satisfaction with services provided. However, a number of other questions indirectly relate to care quality and their findings are also reported here.

Overall, do you feel that the care s/he got from the district and community nurses in the last three months of life was?

- Excellent
- Good
- Fair
- Poor

The above question was asked for each care setting:

- Out-of-hours services
- District and community nurses (DNs)
- General Practitioners
- Care homes
- Hospital doctors
- Hospital nurses

### Overall findings

Responses to these items show that VOICES-SF can detect differences in care quality between care settings and there was considerable variation in the ratings of care quality between care sectors. Care provided by hospices was most consistently rated as 'excellent' (79.0%) and hospitals received the lowest ratings. Care provided by GPs received the third poorest ratings whilst community nurses, out-of-hours services and care homes were rated similarly (Table 9.8).

**Table 9.8: Overall care quality by care setting and PCT (% with weighted frequencies in parentheses. Emboldened figures denote whole sample %)**

	<b>OOHs</b>	<b>DNs</b>	<b>GPs</b>	<b>CHs</b>	<b>Hosp Dr</b>	<b>Hosp Nr</b>	<b>Hospice</b>
<b>Excellent</b>	<b>23.8</b> (163.8)	<b>43.2</b> (243.3)	<b>32.4</b> (281.4)	<b>44.0</b> (173.5)	<b>33.7</b> (297.9)	<b>33.7</b> (320.9)	<b>79.0</b> (162.2)
Berks	20.0 (82.2)	44.6 (151.1)	29.9 (156.6)	50.5 (95.7)	31.5 (175.8)	30.5 (183.5)	76.7 (73.8)
IOW	29.4 (78.2)	41.8 (89.7)	35.0 (119.6)	37.2 (75.4)	37.6 (119.3)	39.2 (134.6)	79.7 (81.6)
<b>Good</b>	<b>47.1</b> (322.5)	<b>42.9</b> (241.7)	<b>39.7</b> (345.3)	<b>42.0</b> (165.6)	<b>34.6</b> (305.1)	<b>33.3</b> (317.0)	<b>13.2</b> (27.1)
Berks	20.3 (29.1)	43.9 (148.7)	40.9 (213.7)	36.9 (69.9)	35.1 (195.8)	34.4 (207.0)	12.0 (11.5)
IOW	43.6 (115.9)	41.3 (88.6)	38.5 (131.5)	47.2 (95.8)	33.0 (104.9)	30.8 (105.7)	15.3 (15.6)
<b>Fair</b>	<b>15.8</b> (108.3)	<b>8.1</b> (45.8)	<b>17.3</b> (150.6)	<b>7.1</b> (28.0)	<b>22.3</b> (196.7)	<b>18.7</b> (177.7)	<b>7.8</b> (16.1)
Berks	18.2 (74.7)	7.6 (25.7)	19.1 (99.7)	7.0 (13.3)	24.1 (134.7)	18.8 (112.7)	11.4 (10.9)
IOW	29.4 (78.2)	8.1 (17.3)	14.9 (51.0)	7.3 (14.8)	19.6 (62.1)	18.9 (64.9)	5.0 (5.1)
<b>Poor</b>	<b>13.2</b> (90.3)	<b>5.7</b> (32.4)	<b>10.6</b> (92.6)	<b>6.9</b> (27.4)	<b>9.4</b> (83.0)	<b>14.3</b> (135.8)	<b>0</b> (0)
Berks	12.7 (52.4)	3.9 (13.3)	10.1 (52.9)	5.5 (10.5)	9.3 (51.8)	16.3 (97.7)	0 (0)
IOW	14.3 (38.0)	8.9 (19.0)	11.6 (39.7)	8.3 (16.9)	9.8 (31.1)	11.1 (38.2)	0 (0)

### Overall Findings by PCT

A mixed picture of quality emerges across the PCTs (Table 9.8). Out-of-Hours services and GPs were rated more highly in the Isle of Wight than in Berkshire East, but DNs and care homes scored more favourably in Berkshire East. The care provided by hospital doctors and nurses was less likely to be rated as 'excellent' in Berkshire. Hospice care also received higher ratings in the Isle of Wight.

These ratings of quality vary by disease type (cause of death). For instance, hospital doctors received more favourable ratings for CVD than for cancer and other diseases (Table 9.9) and almost one fifth of respondents rated the care provided by hospital nurses to patients with 'other' conditions as 'poor' (compared to less than one tenth for CVD patients). Note that sample sizes for hospice are small.

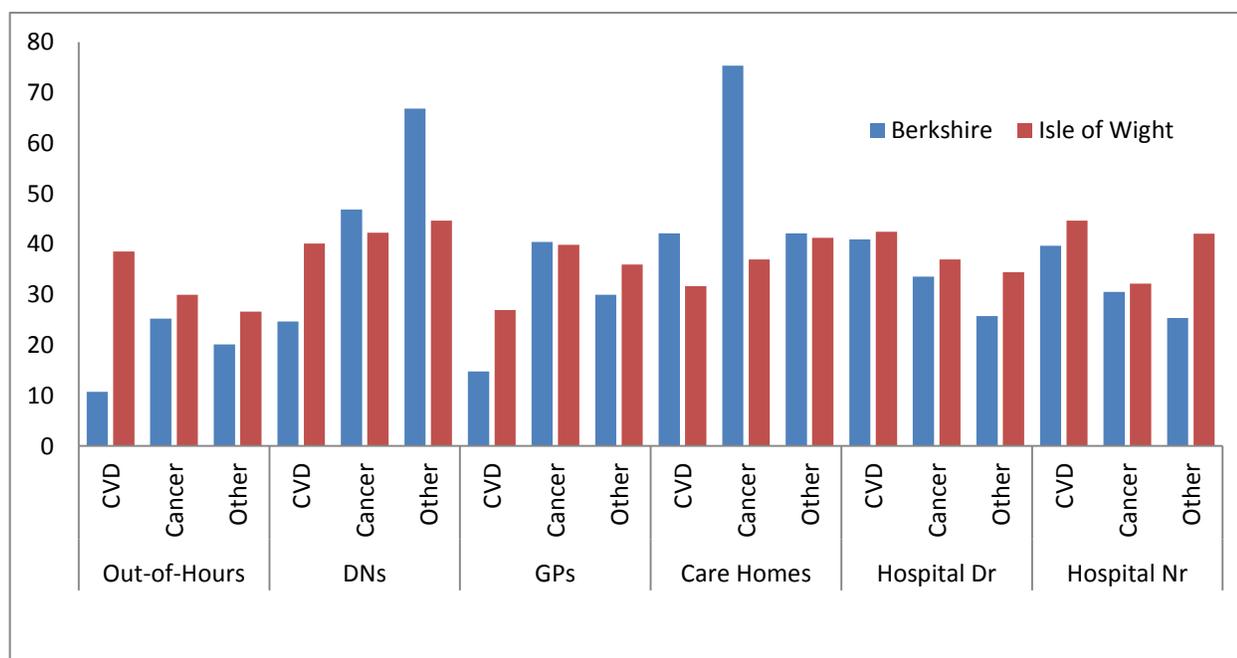
**Table 9.9: Overall care quality by care setting and cause of death (% with weighted frequencies in parentheses)**

	OOHs	DNs	GPs	CHs	Hosp Dr	Hosp Nr	Hospice
<b>Excellent</b>							
CVD	21.8 (27.8)	15.9 (36.9)	19.4 (37.1)	37.8 (33.9)	41.5 (91.3)	41.4 (99.2)	71.7 (6.0)
Cancer	26.9 (76.4)	45.5 (120.9)	40.2 (135.2)	58.8 (52.7)	34.5 (106.8)	31.0 (99.2)	81.1 (133.7)
Other	23.1 (51.8)	54.9 (74.1)	32.5 (93.9)	41.6 (81.4)	29.4 (86.1)	32.2 (103.1)	58.7 (13.9)
<b>Good</b>							
CVD	59.5 (76.0)	52.3 (61.4)	51.1 (97.8)	54.5 (48.9)	38.7 (85.2)	32.0 (76.8)	0 (0)
Cancer	41.3 (117.4)	40.9 (108.6)	36.8 (123.8)	41.2 (36.9)	30.3 (93.9)	35.4 (113.5)	12.2 (20.1)
Other	47.7 (107.2)	35.1 (47.9)	39.4 (114.0)	36.2 (70.9)	31.5 (92.2)	4.9 (95.5)	29.6 (7.0)
<b>Fair</b>							
CVD	14.8 (18.9)	11.3 (13.3)	21.7 (41.5)	2.2 (1.9)	17.3 (38.0)	17.3 (41.4)	28.3 (2.4)
Cancer	19.7 (56.1)	9.3 (24.7)	11.5 (38.6)	0 (0)	22.2 (68.7)	18.6 (59.6)	6.6 (10.9)
Other	11.5 (25.8)	3.7 (5.0)	21.1 (60.9)	10.7 (21.0)	27.1 (79.2)	18.2 (58.2)	11.4 (2.8)
<b>Poor</b>							
CVD	4.0 (5.1)	4.9 (5.8)	7.8 (14.8)	5.6 (5.0)	2.6 (5.7)	9.3 (22.2)	0 (0)
Cancer	12.1 (34.3)	4.4 (11.6)	11.5 (38.7)	0 (0)	13.0 (40.4)	15.0 (48.0)	0 (0)
Other	5.2 (39.8)	6.2 (8.4)	7.1 (20.5)	11.4 (22.4)	12.0 (35.1)	19.8 (63.3)	0 (0)

### Findings by PCT and cause of death

Analysis of overall quality by cause of death can provide an understanding of the nature of the care provided. For instance, as is visible in Figure 9.2, care homes in Berkshire seem to provide a very good level of care for those with cancer (75.3% rating care as excellent overall) but the care for other conditions is considerably poorer (40.5%). Conversely, the care provided to CVD patients by out-of-hours services in Berkshire East was much less likely to be rated as excellent (10.7%).

**Figure 9.2: Percentage rating care as 'excellent' across care settings, stratified by cause of death**



### 9.8.2.1 Hospital Care

72.4% of decedents had spent some time in hospital in the last three months of life.

#### ***Qualitative comments***

Fifty-seven respondents left positive comments regarding hospital care. In terms of overall comments, 23 out of 28 respondents described the hospital care as “excellent”, “first class” or “best” while the remaining five respondents rated the service as “good”. Regarding staff performance, 11 out of 22 respondents rated the hospital staff, in particular, nurses, as “caring” or equivalent attributes such as “understanding” and “kind”. Three respondents appreciated being kept informed about the patient’s conditions by the hospital staff.

*“My mother was extremely well looked after [in hospital]. The nurses would joke and make my Mum laugh and you could see in her eyes how delighted she was when they came and made a fuss of her. What a truly lovely team of nursing staff we were so lucky to have during Mum’s last few months.”* (Berkshire East)

*“The palliative care nurse was excellent. She spent a lot of time with him talking about lots of things, including his travel and holidays. She made his stay in hospital more bearable.”* (Isle of Wight)

*“The ICU [intensive care unit] at [name of hospital] was superb – high staffing levels, high levels of expertise and care, family kept fully informed and involved.”* (Isle of Wight)

Ninety-two respondents made negative remarks about hospital care and unlike for the positive comments where single adjectives were generally used, lengthy descriptions of care were provided. For example, one respondent mentioned that “the whole experience was abysmal”. There was a lack of communication between hospital staff members as observed by three respondents. Similarly, communication between hospital staff and the patient’s family was described as unsatisfactory. Seven respondents were poorly advised about the condition of the patient whilst four respondents were not informed about the imminent death of their relative. Three respondents reported an untimely or “upsetting” end of life discussion and four respondents reported being unable to speak to a doctor or a senior medical consultant. Low levels of staffing were discussed by four respondents and three respondents were unhappy that some staff had poor English language skills.

Hospital discharge also received negative comments. For example, three patients were discharged shortly after surgery and one patient was discharged in “a very frail and confused state”. Four respondents mentioned the negative effects of their relatives being moved from ward to ward.

*“She had four or five different doctors, of varying levels of ability and bedside manner, but the really distressing part was the nursing care. There were countless different nurses, mainly agency staff with terrible attitudes, very unapproachable, but more importantly, severely lacking in both quality and quantity of basic care skills that my Mum so deserves, which left her in pain and embarrassed. I shall never set foot in the hospital again. It is an absolute disgrace.”* (Berkshire East)

*“The last 2 – 3 [hospital] visits were very upsetting as Mum was treated like a leper and in isolation, sometimes missing meals and help with her toilet needs. The nurses were quite impatient and short tempered with her.”* (Berkshire East)

*“Everything was bad in [name of hospital]. I cannot even call it ‘care’. Nursing, communication, feeding seemed non-existent and nobody cared or would enter into discussion or conversation about my sister.”* (Berkshire East)

*“The ward was obviously understaffed and very under-equipped with regard to space, pressure relief mattresses, blankets and pillows. Before being discharged to die at home, she was stuck for 3 nights and days in the corner of a functioning day clinic, due to lack of space on the ward.”* (Isle of Wight)

#### **9.8.2.2. Hospice Care**

15.7% of decedents spent some time in a hospice in the last three months of life.

##### ***Qualitative comments***

Twenty-three respondents wrote positive comments regarding hospice care. Among the 15 general comments, the two most prevalent descriptions were “excellent” and “fantastic” and there were two expressions of deep gratitude. There were 11 compliments in respect to hospice staff. Nurses, for example, were commonly described as “brilliant”, “caring” and kind.

*“The staff at the hospice were very helpful and allowed his family to stay with him 24 hours – a – day. Even though at times there were 20+ family present. With 3 other family members I spent the last 10 days with my father helping with his care and just being there for him, which I will never forget and always be grateful.”* (Isle of Wight)

Five respondents made negative remarks about hospice care and all were related to staff performance. For example, one respondent found that some hospice staff did not handle the patient properly and one respondent found that care deteriorated when the patient was less able to actively engage with the

staff. One respondent raised the issue of lack of privacy in hospice ward.

*“My husband spent only one night in the hospice... Expectations about service within the hospice proved to be unfounded, as due to the fact there was not always a doctor on duty. The procedure to be carried out was cancelled twice.”* (Berkshire East)

### **9.8.2.3. Care Homes**

36.5% of decedents spent some time in a care home during the last three months of their lives.

#### ***Qualitative comments***

Fifty-one respondents gave positive feedback with regard to care home care. The typical description of care was “excellent”, or “very good”. Five respondents felt that the patient was well or “beautifully” looked after. For example, one patient “had her hair done” on a fortnightly basis. In terms of staff performance, the care home staff were usually described as “caring” and “friendly”, followed by “pleasant”, “kind” and “supportive”. Three respondents were pleased with how they were kept informed about their relative’s health or care. Three respondents valued the freedom to visit at any time and stay as long as they wanted and two further respondents described being freely able to discuss any issues they might have or about the services.

*“Mum received the best possible care throughout her illness, a model that the NHS should aspire to. The nurses who cared for Mum all showed genuine concern for her and treated her as if she was part of their family. Mum’s family realise how lucky we were to have her in a good nursing home.”* (Isle of Wight)

*“The staff at [name] Nursing Home were absolutely fantastic. A more caring and professional team would be hard to find anywhere else. My mother had complete trust and faith in the staff from the sisters and nurses to the cleaners and catering support.”*  
(Isle of Wight)

*“I felt my mother was happy there. It is a very difficult job caring for people with dementia. I was very happy with the care.”* (Berkshire East)

Thirty-two respondents had negative comments about care home care. Three respondents found the overall care deficient and six relatives reported that personal hygiene was very poorly managed, for example, two patients were left in soiled clothing. Five respondents reported inadequate communication with the care home regarding the resident’s condition or imminent death.

Twenty comments were related to staff performance, with six of these comments regarding low

staffing levels and two regarding poorly-trained staff. The care home staff were criticised for being unresponsive to residents' needs by five respondents, and two respondents condemned staff for bad conduct. For example, one respondent suspected that the care home might have inflicted injuries to the patients and two other respondents discovered insensitive staff behaviours such as forcing food and fluids to patients. Four respondents were aware of the fact that residents had difficulty in communicating with non-English speaking staff. Four respondents complained about poor laundry services which resulted in residents wearing clothes that were not theirs and loss of personal garments whilst two residents had items go missing during their stay. Lastly, two respondents reported that the care home was not a stimulating environment.

*"I was told that she was unable to eat so they were not going to try. I was not even allowed to give her water."* (Isle of Wight)

*"They frequently worked short-staffed so they were unable to do the job as well as they wished. I wrote numerous complaint letters."* (Isle of Wight)

*"My mother was afraid to complain except once: she told me that she needed to use a commode in the middle of the night and the bedding was wet. The night-nurse reprimanded her for disturbing their night-shift and she was left in wet bedding for the rest of the night. I don't know if she was lifted onto a commode. My mother asked me not to complain. She also said complaints went unheeded, something I noticed as well."* (Berkshire East)

#### **9.8.2.4. Out-of-hours and urgent care**

22.8% of decedents required some form of urgent out-of-hours services in the last three months of life, and 10.5% required such help on four or five occasions. In the majority of these instances (46.6%), the GP or out-of-hours number was called whilst 27.9% telephoned 999, 13% contacted the district nurses, 3.2% contacted the hospice and the remaining 2.3% contacted a Macmillan nurse.

As a result of these actions, 28.9% were visited by the decedent's own GP at home, 22.7% were visited by another GP, 14.8% were advised to go to Accident and Emergency, 11.9% were visited by a nurse at home, and the remainder were given advice over the telephone (2.1%), advised to go to the GP surgery when it opened (2%), were visited by a hospice doctor at home (1.2%) or advised to go to an out-of-hours GP surgery (1%). Respondents were asked whether they felt this was the most appropriate action, 86.7% responded 'yes', 8.6% felt this was not appropriate and 4.6% were unsure.

#### **Qualitative comments**

There were eight positive and two negative comments with regard to the ambulance service. Two respondents rated it as "excellent", five praised the service for a speedy arrival whilst two criticised it

for taking too long to arrive. Two respondents greatly valued the out-of-hours GP services. However, two respondents evaluated the service provided by out-of-hours doctor negatively, either because the doctor did not have much time for the patient or was reluctant to make a home visit.

*“On the 2 occasions that we called the paramedics, they were efficient, respectful, thorough, sympathetic, professional, and responded within minutes.”* (Berkshire East)

*“Ambulance Control directing us to wrong hospital.... Ambulance driver not knowing the way to [hospital]... 12 hours to get an ambulance.”* (Berkshire East)

*“Excellent out-of-hours GP support – could see the home/medical situation.”* (Isle of Wight)

*“There was no palliative care provided and being over the Christmas and New Year period, there was no one available anywhere to help or give care needed. We had to try to cope the best we could on our own.”* (Isle of Wight)

#### **9.8.2.5 District and Community Nurse Care**

District nurses visited 52.9% of decedents at some point in the final three months of life. Of these, 18.4% received daily visits, 8.3% received visits more than once a day, 32.1% had 2–6 visits a week, 15.8% received weekly visits and the remaining 25.6%, less often.

#### **Qualitative comments**

District and community nurses received 20 compliments and four negative comments. “Excellent” and “first-class” were two common praises for the care provided by the district nurses. Negative comments focused on the need for better management of district nurses such as well-coordinated visits and timely contact.

*“The district nursing service and the rapid response nursing care team were all friendly, professional and extremely supportive for the 2 weeks over Christmas and New Year. They visited in pairs 4 times a day and on one occasion in the middle of the night when we needed their help, my sister said they arrived faster than a pizza! Our feelings of gratitude to them are still very strong a year later. I think we were all very lucky.”*

(Berkshire East)

*“The District Nurse who attended to do Mum’s dressings was a breath of fresh air. She was always jolly and considerate and managed to get Mum to laugh. She was also supportive to me, giving advice.”* (Berkshire East)

*“A newly-appointed community matron took over mother’s medical and personal needs and she*

*proved an excellent substitute for the GP service.” (Isle of Wight)*

#### **9.8.2.6 General Practitioner Care**

In the last three months of life, 32.7% of decedents were always or almost always able to see the GP they preferred to see, whilst 10.3% were never able to. Respondents reported positively with regard to the ease of arranging GP home visits: 43% reported that it was very easy to arrange home visits and 41.5% reported that it was fairly easy. However, 11.9% reported that it was fairly difficult and 2.1% that it was very difficult. These findings were very similar across the PCTs.

#### ***Qualitative comments***

There were 22 positive and 26 negative comments with regard to GP service. In terms of positive evaluation, GPs were rated as “excellent” and “helpful”. GPs who were always available or happy to be contacted were appreciated by respondents. The negative comments were based on concerns that the GP was uncaring, reluctant to meet the patient, made a wrong diagnosis or did not take the patient seriously.

*“He [the GP] offered her choices about her care and mobilised the district nursing service.”*  
(Berkshire East)

*“Our GP on the other hand could not have been more helpful or supportive...The care from the GP was second to none.”* (Berkshire East)

*The GP who saw her [name of medical centre] was not in the slightest bit interested in my Mother’s state of health... The GP in question was one of the worst I have ever met, totally uncaring, uninterested and clearly had other things on her mind.”* (Berkshire East)

#### **9.8.2.7. Care provided by charitable organisations – qualitative comments**

Macmillan nurses received 11 positive comments and five criticisms. Regarding positive evaluation, respondents often prized Macmillan nurses for their “excellent” service as well as for their dedication to patient care. However, three respondents did not find Macmillan nurses “useful” or “helpful”.

The Hospice at Home (HAH) service received eight compliments and one negative comment. Most respondents who praised the HAH staff described them as “brilliant”. The only criticism was given by a respondent who reported that the service upset their relative on several occasions. Two respondents praised Marie Curie services.

*“Macmillan team were fantastic. Very supportive and helped my mother a lot.”*  
(Berkshire East)

*"The Macmillan nurses were very caring and informative and sensitive to the situation."*  
(Berkshire East)

*"Twice I contacted Macmillan as advised by the hospital and GP. They were useless. I understood they would send out someone to discuss our concerns and give advice. I was told they did not do home visits."* (Berkshire East)

*"Hospice at Home in the last 24 hours were good and supportive."* (Isle of Wight)

*"The hospice at home team were not as good and managed to upset my father on several occasions."* (Isle of Wight)

#### **9.8.2.8. Care provided by Social Services and home care organisations – qualitative comments**

Social services received four positive and 12 negative comments. Respondents valued social services greatly for treating the patient with care and for providing information about available help to the patient. Social workers were criticised by four respondents (mainly for being unwilling to help privately funded carers to source care homes or for being slow to help) and praised by one. Three respondents were distressed about struggling to obtain care benefits for their relative. One respondent reported that their relative received "good" home care, but four respondents were disappointed with home care services.

*"Everything about the home care was excellent. I cannot think of a single thing to criticise and I am very grateful for the opportunity to record my impressions as a recipient of community healthcare."* (Berkshire East)

*"Dad had the same social worker for nearly eight years and she was a saint. ..Whilst he was in hospital, she changed jobs and worked in the dementia clinic but she was allowed to still have contact with him. In fact, two days before he died, she spent an hour at his bedside. Without her help I do not know sometimes how I would have managed."* (Isle of Wight)

*"Felt quite like a battle to get the care visits we did, except District Nurses who were the backbone of the service."* (Berkshire East)

*"I was worried that she was unable to get into a bath. I spoke to Social Service and requested help with fitting some hand rails, but was told there was a waiting list of 47 weeks."*  
(Isle of Wight)

### 9.8.3. Dignity and respect

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

All of the time

Most of the time

Some of the time

Never

The above question was asked for each care setting:

- District and community nurses (DNs)
- General Practitioners
- Care homes
- Hospital doctors
- Hospital nurses
- Doctors in the last 2 days of life
- Nurses in the last 2 days of life

#### **Overall Findings**

As was the case for overall care quality, there was variation in the proportion of patients being treated with respect and dignity between care settings. For instance, hospice doctors were most likely to treat patients with respect and dignity all of the time (91.8%) whilst hospital nurses were least likely (48.4%). Hospital doctors did not fare much better than hospital nurses but in the last two days and across care settings, the doctors and nurses received higher ratings. Findings are summarised in Tables 9.10 and 9.11 (emboldened data).

#### **Findings by PCT**

The proportion of patients always being treated with dignity and respect by the community nurses was higher in Berkshire East than in the Isle of Wight (Table 9.10), as was the case for care homes. However, for all other care settings, staff in the Isle of Wight were more likely to treat patients with dignity and respect all of the time (Tables 9.10 and 9.11).

**Table 9.10: Dignity and respect by care setting and PCT (% with weighted frequencies in parentheses. Emboldened figures denote whole sample %)**

	<b>DNs</b>	<b>GPs</b>	<b>CHs</b>	<b>Hosp Dr</b>	<b>Hosp Nr</b>
<b>All of the time</b>	<b>81.5</b> (467.6)	<b>70.6</b> (632.0)	<b>68.6</b> (275.9)	<b>54.4</b> (468.7)	<b>48.4</b> (437.5)
Berks	83.1 (296.4)	69.4 (373.1)	76.5 (154.1)	53.9 (305.4)	46.8 (272.4)
IOW	78.7 (32.4)	72.4 (258.9)	60.6 (121.8)	55.4 (163.3)	51.1 (165.2)
<b>Most of the time</b>	<b>14.0</b> (80.6)	<b>20.2</b> (180.4)	<b>23.3</b> (93.7)	<b>27.0</b> (233.0)	<b>27.8</b> (251.4)
Berks	13.5 (48.1)	21.6 (116.3)	14.4 (29.0)	26.1 (147.8)	28.3 (164.8)
IOW	14.9 (32.4)	17.9 (64.1)	32.2 (64.7)	28.9 (85.2)	26.8 (86.6)
<b>Some of the time</b>	<b>2.4</b> (13.8)	<b>5.7</b> (50.7)	<b>8.2</b> (32.8)	<b>17.2</b> (148.0)	<b>22.7</b> (205.6)
Berks	1.1 (3.9)	5.9 (16.5)	9.1 (18.3)	18.3 (10.2)	23.3 (135.7)
IOW	4.6 (9.9)	5.4 (19.3)	7.3 (14.6)	15.0 (44.3)	21.6 (69.9)
<b>Never</b>	<b>2.1</b> (11.9)	<b>3.6</b> (31.8)	<b>0</b> (0)	<b>1.4</b> (12.0)	<b>1.1</b> (10.2)
Berks	2.3 (8.1)	3.1 (16.5)	0 (0)	1.8 (10.2)	1.5 (8.6)
IOW	1.8 (3.9)	4.3 (15.3)	0 (0)	0.6 (1.8)	0.5 (1.6)

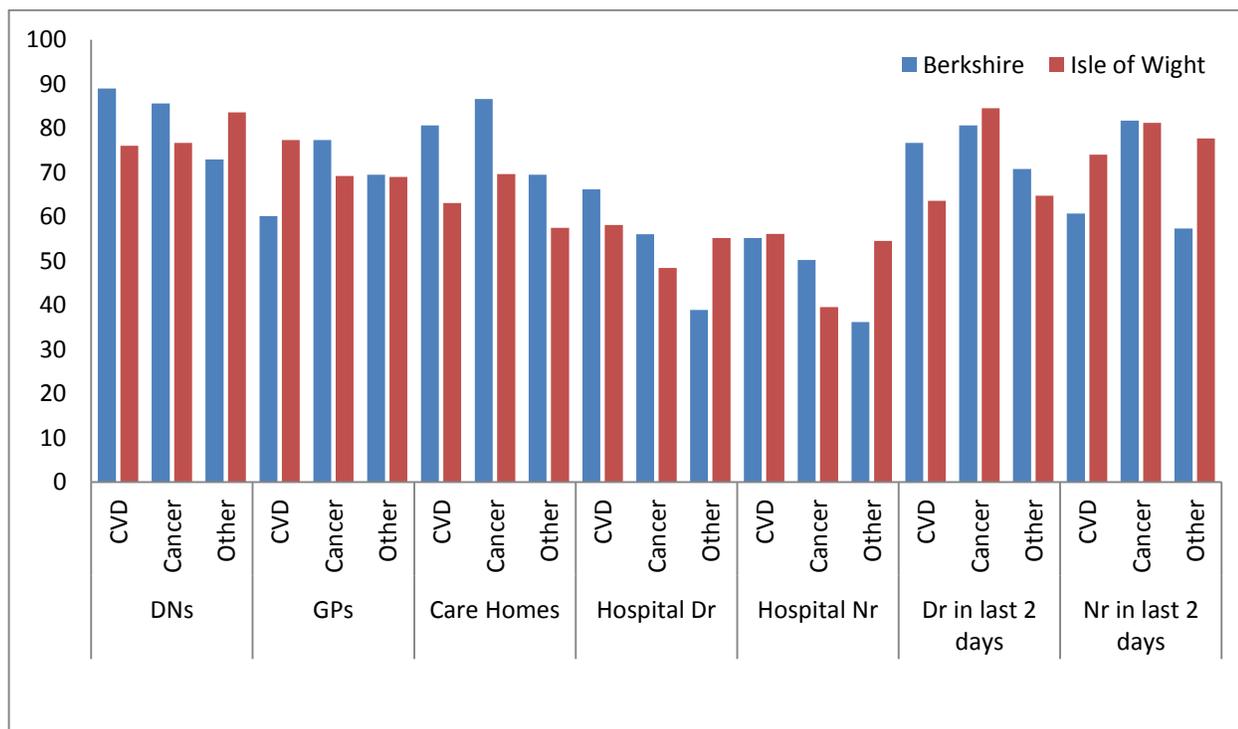
**Table 9.11: Dignity and respect by care setting and PCT (% with weighted frequencies in parentheses. Emboldened figures denote whole sample %)**

	<b>Hospice Dr</b>	<b>Hospice Nr</b>	<b>Last 2 days - Dr</b>	<b>Last 2 days - Nr</b>
<b>All of the time</b>	<b>91.8</b> (184.3)	<b>87.2</b> (179.3)	<b>74.1</b> (580.7)	<b>71.3</b> (642.9)
Berks	87.1 (88.3)	77.9 (83.7)	75.1 (374.5)	68.3 (388.6)
IOW	96.7 (96.5)	97.5 (95.6)	72.3 (206.2)	76.5 (254.8)
<b>Most of the time</b>	<b>4.8</b> (9.7)	<b>7.3</b> (14.9)	<b>17.4</b> (136.7)	<b>17.8</b> (160.5)
Berks	7.8 (8.0)	11.6 (12.5)	17.1 (85.3)	18.6 (105.8)
IOW	1.8 (1.8)	2.5 (2.5)	18.0 (51.3)	16.4 (54.7)
<b>Some of the time</b>	<b>2.6</b> (5.2)	<b>4.7</b> (9.7)	<b>8.5</b> (66.5)	<b>10.7</b> (96.1)
Berks	3.5 (3.6)	9.1 (9.7)	7.8 (38.8)	13.1 (74.7)
IOW	1.6 (1.6)	0 (0)	9.7 (27.7)	6.5 (21.5)
<b>Never</b>	<b>0.8</b> (1.5)	<b>0.8</b> (1.5)	<b>0</b> (0)	<b>0.2</b> (1.9)
Berks	1.5 (1.5)	1.4 (1.5)	0 (0)	0 (0)
IOW	0 (0)	0 (0)	0 (0)	0.6 (1.9)

### **Findings by PCT and cause of death**

In the last two days, cancer patients were more likely to be treated with dignity and respect all of the time than those with CVD or other causes of death and this trend was apparent across the two PCTs. In Berkshire East, ratings for hospital doctors and nurses are particularly low for patients dying of 'other causes', whilst for CVD, dignity and respect ratings were higher (Figure 9.3).

**Figure 9.3: Percentage treated with dignity and respect ‘all of the time’ across care settings, stratified by cause of death**



**Qualitative comments**

Regarding dignity and respect, the majority of comments were associated with care provided in hospitals, generally with negative comments. However, it should be noted that there is overlap between the comments for ‘overall quality of care’ and ‘respect and dignity’. We have focused the latter on concepts such as hygiene care, provision of food and drink and emotional contact.

**Hospital Care**

*“The last few days of his life were made as comfortable as is possible in such circumstances and he would have had no complaints I am sure.”*

(Berkshire East)

*“I hope I am not treated in that way. Nobody had the time to really see what was needed or cared. He was old and frail, so why bother was the opinion of staff and doctors.”*

(Berkshire East)

Several of the respondents noted an apparent lack of understanding of the particular needs of patients with cognitive impairments:

*“His care in [name] Ward demonstrated a huge deficiency in the care of elderly demented patients.” (Isle of Wight)*

*“As my mother suffered from dementia, I feel that her special needs were not understood... I tried several times to speak to a doctor about her condition and treatment, but was rarely successful in this. I’m afraid the nurses seemed cold and unfeeling to her pain.”*  
(Berkshire East)

The provision of food in hospital seemed to be a source of concern for several respondents. Eleven respondents reported inadequate nursing care with feeding patients. For example, 3 respondents observed that food and drinks were put out of reach and 4 patients received insufficient help with eating. This seemed to be a particular issue for the older patients.

*“If he didn’t want his meal it seems he was not encouraged, the food was taken away. I was not allowed to visit at meal times. I feel I could have encouraged him if it had been allowed. He lost a lot of weight in hospital.”* (Berkshire East)

*“She lost weight dramatically whilst there [hospital] and I frequently found her ‘meal’ untouched on a table out of her reach. She rarely had water available and when she was eventually discharged, the hospital failed to inform me.... I was disgusted with the treatment she received.”*  
(Berkshire East)

*“Difficult to assess care in hospital, but we were somewhat unhappy that she usually seemed, cold, under-dressed, thirsty and unable to reach drinks/meals, etc. There were so many cold cups of tea not within her reach and we don’t know (I have doubts about) how much help she was given with drinks and meals.”* (Isle of Wight)

Thirteen respondents reported that their relative received no care, especially no help with personal hygiene. For example, 1 patient was “neglected for 10 days” and another patient was found in soiled bedding.

*“On several visits [to the hospital], my mother was laid there in her own excrement. The stench was unbelievable.”* (Isle of Wight)

*“We called for a bedpan for her and a few minutes later one appeared. After she had urinated into it, it was placed on her bedside table next to her uneaten supper. It was still there when we left 2 hours later... Her call button didn’t work and the nursing staff was aware of this.”*  
(Berkshire East)

*"[Hospital] was terrible. She could not get out of bed to look after herself so she was not looked after. My sister went in next morning. She was soaking wet. She had not been looked after at all. Anyway, they sent her back to the home later that day, soaking wet. She had not been changed. To think my mother was 97 years old left on her own not able to get out of bed to toilet and was left like that for 2 days." (Berkshire East)*

### **Care provided by Care Homes**

The comments regarding care homes were more mixed. Five reported positively, and three reported negatively.

*"The care at [name of care home] could not have been more attentive and thoughtful. The staff were in tune to my father's needs and showed their appreciation of his lovely personality, which somehow managed to shine through even after his crippling - in mind and body - stroke. It meant a lot to us that they recognised Dad's qualities and personality and showed that they treated him with dignity, respect, and loving care." (Berkshire East)*

*"My mother was in a care home near me for the last 9 years of her life. She gradually deteriorated with dementia. The care home was marvellous with her. I think a lot of homes would have moved her to a nursing home but they said that they would like to look after her until the end. They held a marvellous party for her 100<sup>th</sup> birthday." (Berkshire East)*

*"I always felt that my Mum was neglected so much of the time, due lack of staff and poorly trained staff. She suffered sores on her bottom and was in lots of pain from it. At times I felt she was treated like a number." (Isle of Wight)*

### 9.8.4. Co-ordination of care

Did the hospital services work well together with his/her GP and other services outside the hospital?

Yes definitely

Yes to some extent

No they did not work well together

#### Overall Findings

29.4% responded that hospital services worked well with community services whilst 34.7% reported that they did not work well together. The remainder reported that the services worked well together to some extent (Table 9.12).

**Table 9.12: Co-ordination of care (% with weighted frequencies in parentheses. Emboldened figures denote whole sample %)**

	<b>Did the hospital services work well together with her GP and other services outside of the hospital?</b>	<b>When she was at home in the last three months of life, did all these services work well together?</b>
<b>Yes, definitely</b>	29.4 (192.0)	43.5 (277.5)
Berkshire East	24.1 (100.6)	38.2 (149.3)
Isle of Wight	38.7 (91.4)	52.0 (128.1)
<b>Yes, to some extent</b>	35.9 (234.0)	40.7 (259.3)
Berkshire East	39.1 (163.0)	44.7 (174.8)
Isle of Wight	30.1 (71.1)	34.3 (84.4)
<b>No, they did not work well together</b>	34.7 (226.4)	15.8 (101.0)
Berkshire East	36.7 (153.0)	17.2 (67.2)
Isle of Wight	31.1 (73.4)	13.7 (33.8)

#### Findings by PCT

A greater proportion of respondents from the Isle of Wight reported that services ‘definitely’ worked well together (Table 9.12).

#### Qualitative comments

Three respondents reported effective communications across different care teams/departments where each party was aware of what was happening. Two respondents commented on how well the different healthcare agencies worked together.

*“At all times each department seemed fully aware of what was happening. I was so impressed with the way they must all have been in touch with each other. What a team!”*

(Berkshire East)

*“The whole ‘end of life team’ was tremendous and worked together right until the end...All the agencies worked together and the team from the general practice were well-informed at all time.” (Berkshire East)*

Seven respondents reported poor communication across health and social care. Among them, four related to communication between hospital and the surgery, and one between hospitals. One respondent mentioned that the GP did not work well with the hospice, another respondent spoke of “an abysmal lack of communication between the GP surgery and the district nurses”.

*“During her final hospital stay, there seemed to be no reference to her previous recent hospital medical history, and staff were very bad at communicating with each other and reading notes on her current treatment.” (Isle of Wight)*

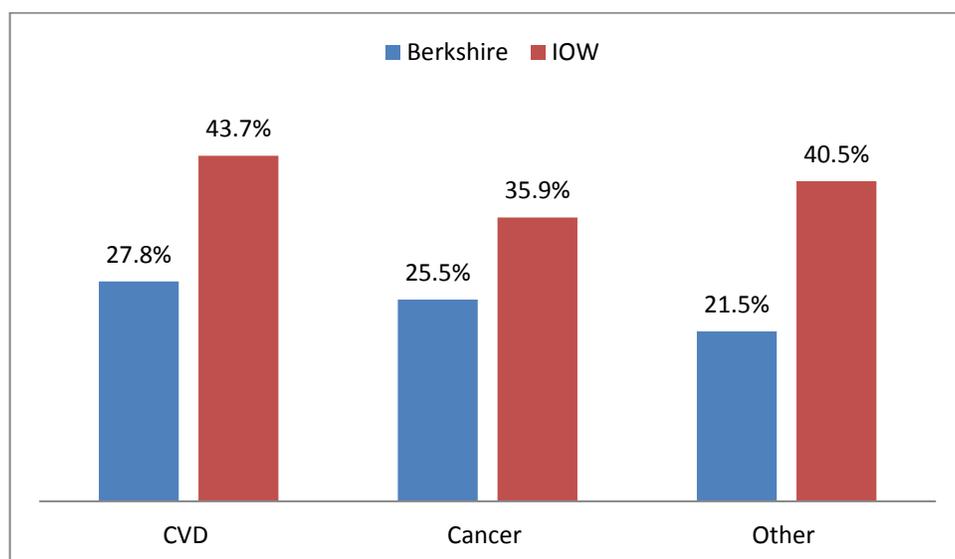
*“The communication between the hospital staff who carried out various diagnostic investigations and my mother and her GP was very poor indeed.” (Berkshire East)*

*“It [the care] was disjointed. At times we felt helpless. When we asked for help, we didn’t get it.” (Isle of Wight)*

### **Findings by PCT and cause of death**

Informants whose relative died of ‘other causes’ and were cared for in Berkshire East were least likely to report that hospital and community services worked well together whilst CVD patients in the Isle of Wight were most likely (Figure 9.4).

**Figure 9.4: Percentage reporting hospital services ‘definitely’ worked well with other services outside the hospital, stratified by cause of death**



When s/he was at home in the last three months of life, did all these services [home services such as community nurses, home carers, occupational therapists] work well together?

Yes definitely

Yes to some extent

No, they did not work well together

## Overall Findings

43.5% reported that community based services worked well together whilst 15.8% reported that they did not work well together.

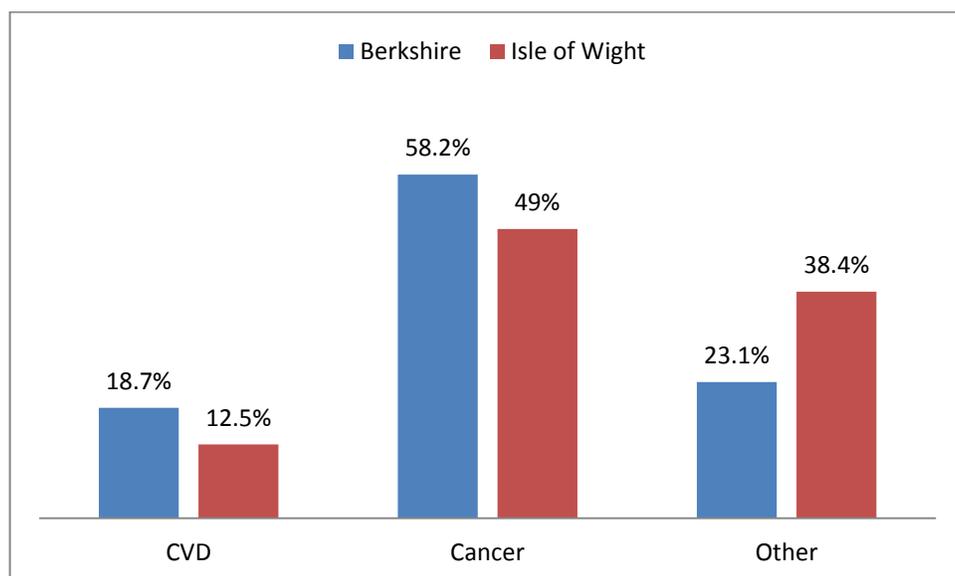
## Findings by PCT

A considerably greater proportion of relatives in the Isle of Wight than in Berkshire East reported that community services worked well together (Table 9.12). There was also a higher proportion reporting that they did not work well together in Berkshire East (17.2% compared to 13.7%).

## Findings by PCT and cause of death

There were marked differences in the experiences of those with different conditions regarding continuity of and communication between community services. For instance, those who died from CVD, regardless of PCT, were much less likely to report that community services worked well together than those who died from cancer (Figure 9.5).

**Figure 9.5: Percentage reporting community services 'definitely' worked well with each other, stratified by cause of death**



### 9.8.5. Relief of pain and suffering

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

Completely all of the time

Completely some of the time

Partially

Not at all

The above question was asked for the following care settings:

- a. Care at home (question featured above)
- b. Care home
- c. Hospital
- d. Hospice

Note that data on pain control in the last two days was gathered using a different question format and is therefore discussed in Section 9.8.6.

#### Overall findings

There was considerable variation in the provision of adequate pain relief between care sectors (Table 9.13). As might be expected, hospices were most likely out of all care settings to relieve pain, 'Completely, all of the time' (59.6%). Pain relief was poorest in the home setting with the majority of respondents reporting that pain was only, 'Partially' relieved (43.7%), or not relieved at all (6.4%).

**Table 9.13: Pain relief across care settings (% with weighted frequencies in parentheses)**

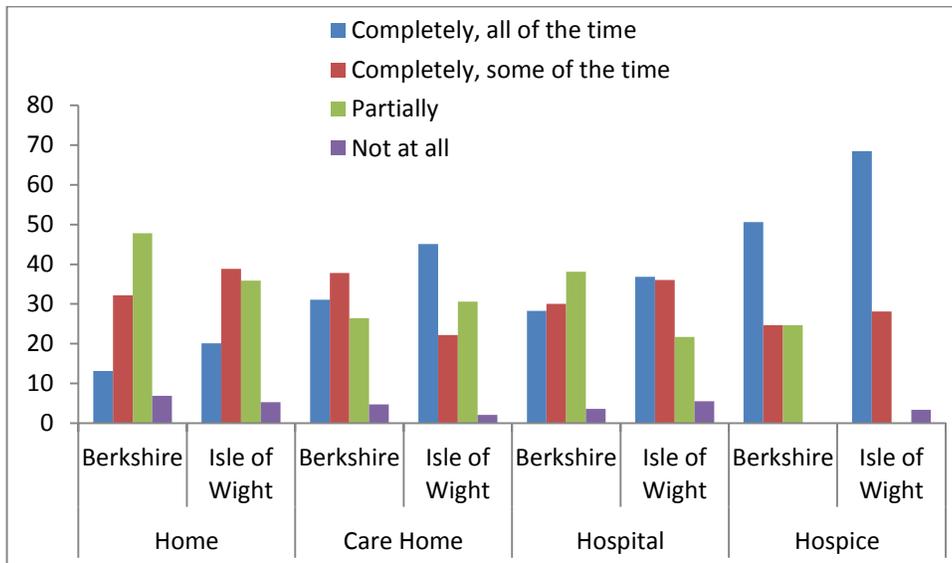
	Home	Hospital	CHs	Hospice
<b>Completely, all of the time</b>	15.5 (94.7)	31.2 (225.1)	38.0 (110.8)	59.6 (106.0)
<b>Completely, some of the time</b>	34.5 (211.3)	32.1 (231.4)	30.2 (88.3)	26.8 (49.6)
<b>Partially</b>	43.7 (267.5)	32.5 (234.4)	28.4 (82.8)	12.1 (21.5)
<b>Not at all</b>	6.3 (38.8)	4.2 (30.4)	3.4 (9.9)	1.6 (2.8)

#### Overall Findings by PCT

Overall, pain relief across all settings was better managed in the Isle of Wight than in Berkshire East (Figure 9.6). In the hospice setting in the Isle of Wight, pain was very well managed with 96.6% of respondents reporting that pain was completely relieved (all or some of the time). Hospices in Berkshire East received slightly poorer ratings in this regard. At home and in the hospital, pain was also

better managed in the Isle of Wight (Figure 9.6).

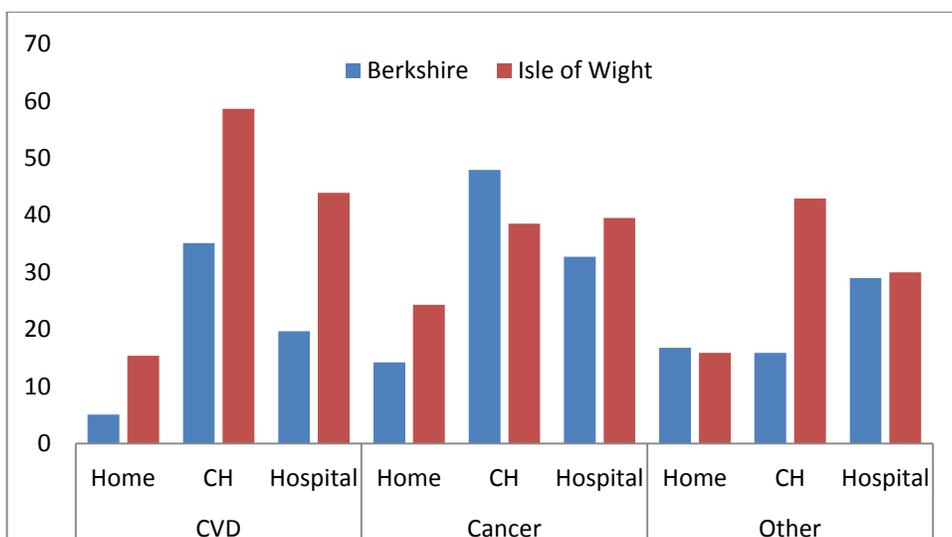
**Figure 9.6: How well pain was relieved across care settings and PCTs (in %)**



**Findings by PCT and cause of death**

There was no consistent pattern of scores across the disease types (Figure 9.7). Pain control in hospices was not assessed because so few non-cancer patients received hospice care.

**Figure 9.7: Percentage reporting that pain was relieved ‘Completely, all of the time’ across care settings, stratified by cause of death**



### **Qualitative comments on pain control**

*“My mother’s GP did all she could to ensure pain control, contacting the hospital and phoning me to let me know what was happening. She visited my mum on her first night home, kneeling down by her bed and cuddling her. My mother really appreciated this kind action.”* (Berkshire East)

*“Mum was in a lot of pain and relied on pain relief at set intervals. There were occasions when staff were too busy to administer drugs on time or if she was moved ward the continuity of care took time to ‘kick in’.”* (Berkshire East)

*“She was given painkillers by a nurse but not any water to take them with. There was no water glass or jug on her table. When we asked the nurse, she said, ‘I don’t know where the lady who does the water has gone’...”* (Berkshire East)

### 9.8.6. Support in the last two days of life

During the last two days of life, the vast majority of decedents remained in one place (97.8%). 48.5% were in a hospital all of the time, 26.5% in a care home, 12.3% at home and 10.6% remained in a hospice.

This section is described using questionnaire items that address:

- i. Personal Care Needs
- ii. Nursing care needs
- iii. Privacy
- iv. Relief of pain and other symptoms
- v. Spiritual support
- vi. Emotional Support
- vii. Support to stay in preferred place.

#### ***Qualitative comments***

20 respondents reported that the patient had received good quality of care in the last days of life. Three respondents rated the care as “good”, three respondents were glad that the patient did not suffer in the final days of life and two respondents were able to be with the patient before he/she passed away. Eight comments were related to the caring personality of or thoughtful arrangements by the staff such as a private room or a visit from a priest/church minister. 3 respondents reported that family were well treated and supported by the staff.

#### **i. Personal Care Needs**

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help s/he received in the last two days:

– There was enough help available to meet his/her personal care needs such as toileting needs

Strongly agree

Agree

Neither agree nor disagree

Strongly disagree

#### **Overall findings**

Personal care needs were not always met in the last two days of life (Table 9.14).

**Table 9.14: Care needs and privacy in the last two days (% with weighted frequencies in parentheses)**

		All sample	Berkshire East	Isle of Wight
<b>There was enough help with personal care needs</b>	Strongly agree	38.6 (472.7)	38.5 (282.6)	38.6 (190.2)
	Agree	38.5 (471.5)	39.1 (286.6)	37.6 (184.9)
	Neither agree not disagree	10.8 (131.8)	9.8 (72.1)	12.1 (59.7)
	Disagree	8.9 (108.9)	10.1 (74.1)	7.1 (34.7)
	Strongly disagree	3.3 (40.6)	2.5 (18.2)	4.6 (22.6)
<b>There was enough help with nursing care needs</b>	Strongly agree	38.5 (464.2)	38.0 (275.6)	39.3 (188.6)
	Agree	37.7 (454.0)	38.5 (279.1)	36.4 (174.9)
	Neither agree not disagree	12.4 (149.8)	12.5 (90.8)	12.3 (59.0)
	Disagree	8.7 (104.4)	9.4 (67.1)	7.6 (36.5)
	Strongly disagree	2.7 (33.0)	1.7 (12.2)	4.3 (20.8)
<b>The bed area and surrounding environment had adequate privacy</b>	Strongly agree	50.0 (603.8)	49.1 (360.4)	51.5 (243.5)
	Agree	30.9 (372.7)	33.6 (246.8)	26.6 (126.0)
	Neither agree not disagree	8.4 (100.9)	8.6 (63.0)	8.0 (37.9)
	Disagree	6.3 (76.6)	5.4 (39.6)	7.8 (36.9)
	Strongly disagree	4.4 (53.1)	3.3 (24.1)	6.1 (28.9)

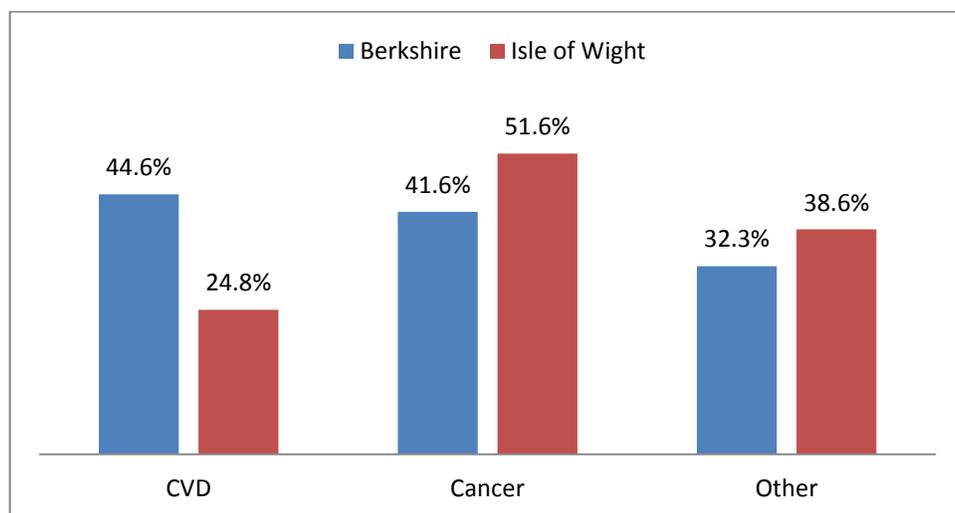
### Findings by PCT

Again there was little variation between the PCTs (Table 9.14).

### Findings by PCT and cause of death

Patients in Berkshire East with CVD were the least likely to receive enough help with personal care in the last two days whilst cancer patients in the Isle of Wight were the most likely (Figure 9.8).

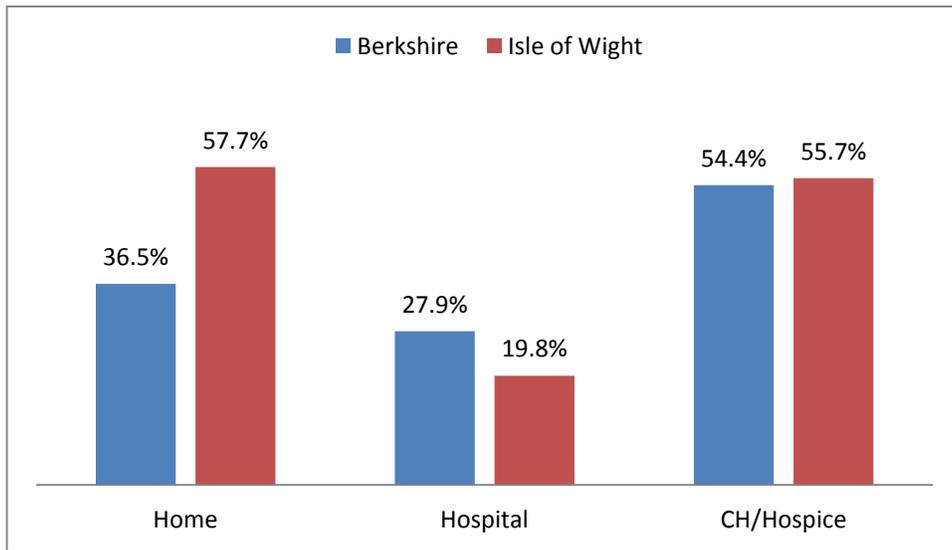
**Figure 9.8: Percentage reporting enough help to meet personal care needs in the last two days, stratified by cause of death**



### Findings by PCT and place of death

Patients who died in hospital were less likely to receive enough help with personal care than patients who died at home or in a hospice/care home. Although this was the case in both PCTs, considerably fewer patients in hospital in the Isle of Wight than in Berkshire East received sufficient help. There was also some variation between PCTs for those who died at home: patients in the Isle of Wight were more likely to receive sufficient help with personal care (Figure 9.9).

**Figure 9.9: Percentage reporting enough help to meet personal care needs in the last two days ('Strongly agree'), stratified by place of death**



## ii. Nursing Care Needs

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help s/he received in the last two days:

– There was enough help with nursing care, such as giving medicine and helping him/her find a comfortable position in bed

Strongly agree

Agree

Neither agree nor disagree

Strongly disagree

### Overall findings

Although the majority of respondents agreed that their relative had enough help with nursing care in the last two days, 11.5% disagreed and only 38.5% strongly agreed (Table 9.14).

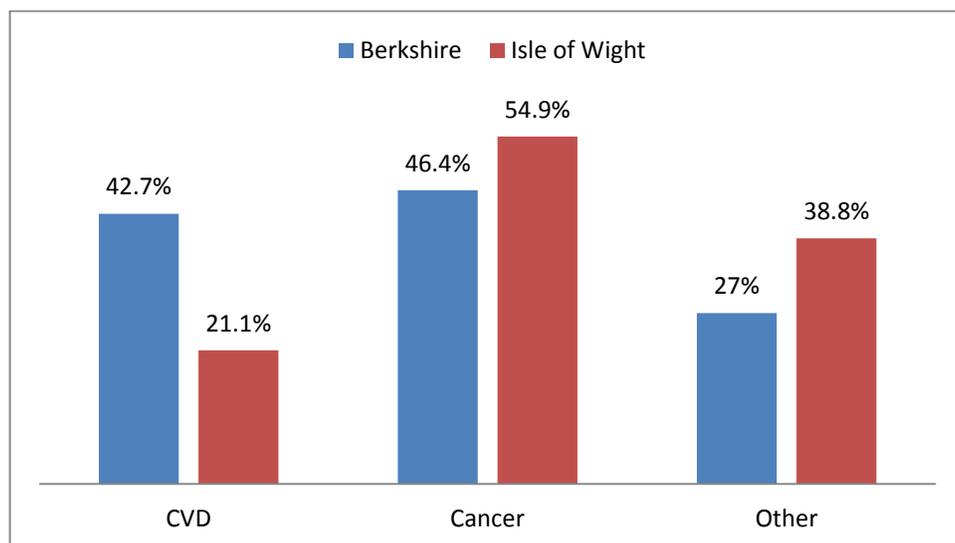
### Findings by PCT

Little variation was apparent across the two PCTs (Table 9.14).

### Findings by PCT and cause of death

Patients with CVD in the Isle of Wight were the least likely to receive sufficient nursing care in the last two days whilst cancer patients in the Isle of Wight were the most likely (Figure 9.10).

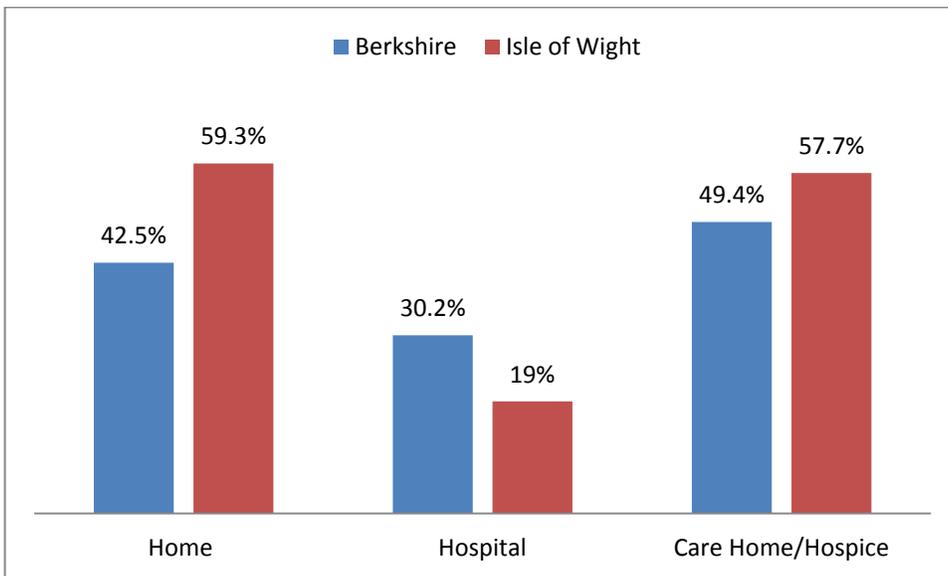
**Figure 9.10: Percentage reporting enough help with nursing care in the last two days, stratified by cause of death**



### Findings by PCT and place of death

When stratified by place of death within PCT, the hospital setting again received the poorest scores. In the Isle of Wight, for example, only 19% of respondents strongly agreed that their relative received enough nursing care in the last two days. Berkshire East hospitals scored considerably higher (30.2%) but still much lower than for care provided at home or in a hospice/care home (Figure 9.11).

**Figure 9.11: Percentage reporting enough help with nursing care in the last two days ('Strongly agree'), stratified by place of death**



### iii. Privacy

Please look at the following statements and tick the answer box that corresponds most with your opinion about the help s/he received in the last two days:

– The bed area and surrounding environment had adequate privacy for him/her

Strongly agree

Agree

Neither agree nor disagree

Strongly disagree

#### **Overall findings**

Half of all patients had sufficient privacy in the last two days of life. Only 10.7% of informants disagreed with the above statement (Table 9.14).

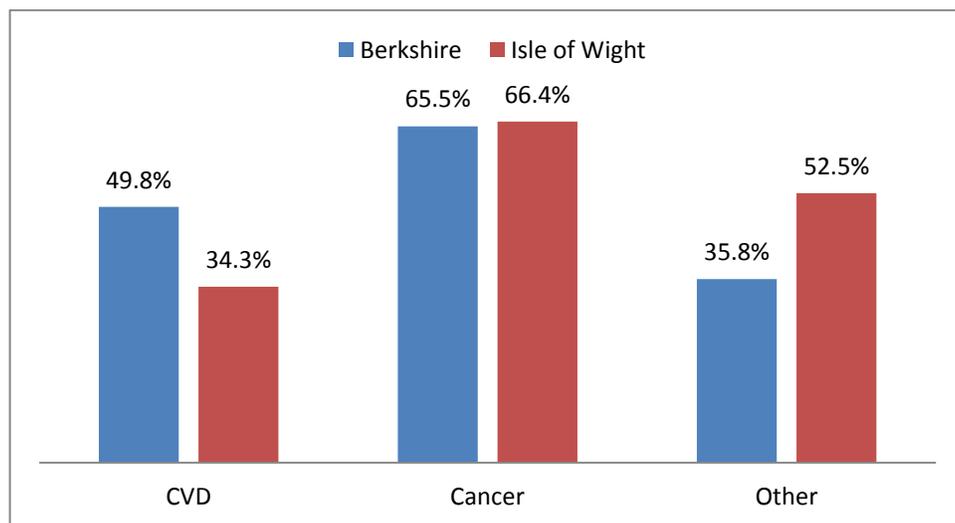
#### **Findings by PCT**

Although there was little difference between PCTs, a slightly larger proportion of informants in the Isle of Wight reported that their relative had sufficient privacy (Table 9.14). However, the proportion of informants who disagreed with this statement was also slightly higher in the Isle of Wight (13.9% compared to 8.7%).

#### **Findings by PCT and cause of death**

Cancer patients were more likely to have had enough privacy and CVD patients in the Isle of Wight were the least likely (Figure 9.12).

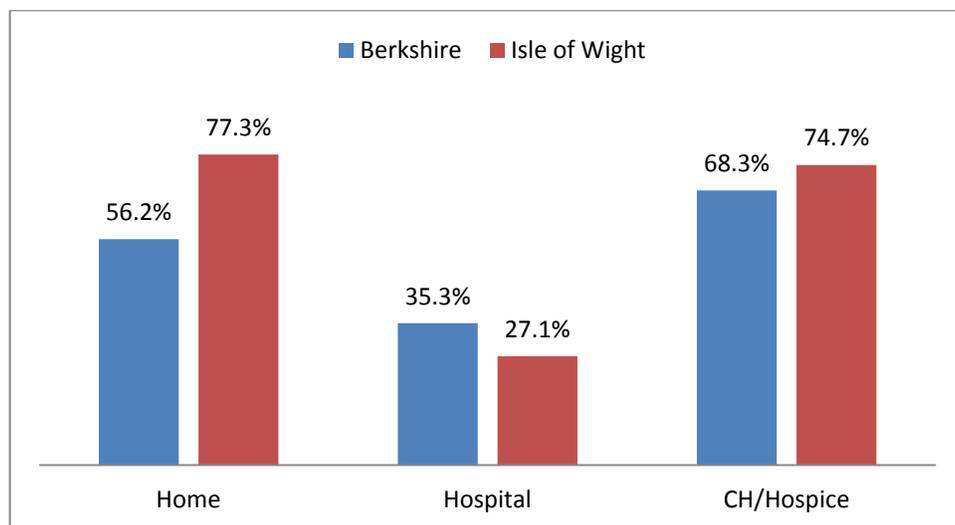
**Figure 9.12: Percentage reporting adequate privacy in the last two days ('Strongly agree'), stratified by cause of death**



### Findings by PCT and place of death

Patients who died in hospital, in both PCTs, were the least likely to have had enough privacy in the last two days (Figure 9.13).

**Figure 9.13: Percentage reporting adequate privacy in the last two days ('Strongly agree'), stratified by place of death**



### Qualitative comments

*“Several months as a guest of the NHS in a crowded and noisy ward is not only an unpleasant end but also a national disgrace.”* (Berkshire East)

#### iv. Relief of Pain

During the last two days, how do you rate the overall level of support given in the following areas from those caring for him/her?

– Relief of pain

Excellent

Good

Fair

Poor

#### Overall findings

Across the sample, 39.8% of patients received excellent pain relief in the last two days. However, 7.3% remained in pain and a further 11.5% received only ‘fair’ levels of pain relief (Table 9.15).

**Table 9.15: Support and symptom relief in the last two days (% with weighted frequencies in parentheses)**

		All sample	Berkshire East	Isle of Wight
<b>Relief of pain</b>	Excellent	39.8 (386.5)	38.8 (236.2)	41.5 (150.3)
	Good	41.4 (401.7)	43.7 (266.1)	37.5 (135.6)
	Fair	11.5 (111.5)	11.7 (71.1)	11.2 (40.4)
	Poor	7.3 (70.7)	5.8 (35.2)	9.8 (35.5)
<b>Relief of symptoms other than pain</b>	Excellent	34.5 (334.6)	30.9 (192.4)	41.1 (142.2)
	Good	41.4 (401.4)	44.0 (274.4)	36.7 (126.9)
	Fair	15.7 (152.1)	16.3 (101.6)	14.6 (50.5)
	Poor	8.4 (81.1)	8.8 (55.1)	7.5 (26.0)
<b>Spiritual support</b>	Excellent	34.8 (197.5)	34.8 (130.2)	34.9 (67.3)
	Good	31.2 (176.7)	28.8 (107.7)	35.7 (69.0)
	Fair	14.3 (81.0)	18.6 (69.5)	6.0 (11.5)
	Poor	19.7 (111.9)	17.8 (66.7)	23.4 (45.3)
<b>Emotional support</b>	Excellent	37.9 (327.4)	35.9 (194.9)	41.0 (132.5)
	Good	31.8 (275.1)	31.4 (170.2)	32.5 (104.9)
	Fair	16.7 (144.4)	17.1 (92.5)	16.1 (51.8)
	Poor	13.6 (118.0)	15.6 (84.5)	10.4 (33.5)
<b>Support to stay where he wanted to be</b>	Excellent	48.8 (390.0)	44.1 (220.9)	56.6 (169.1)
	Good	30.3 (242.4)	32.9 (164.9)	26.0 (77.5)
	Fair	9.7 (77.6)	9.0 (45.1)	10.9 (32.5)
	Poor	11.2 (89.4)	14.0 (70.0)	6.5 (19.4)

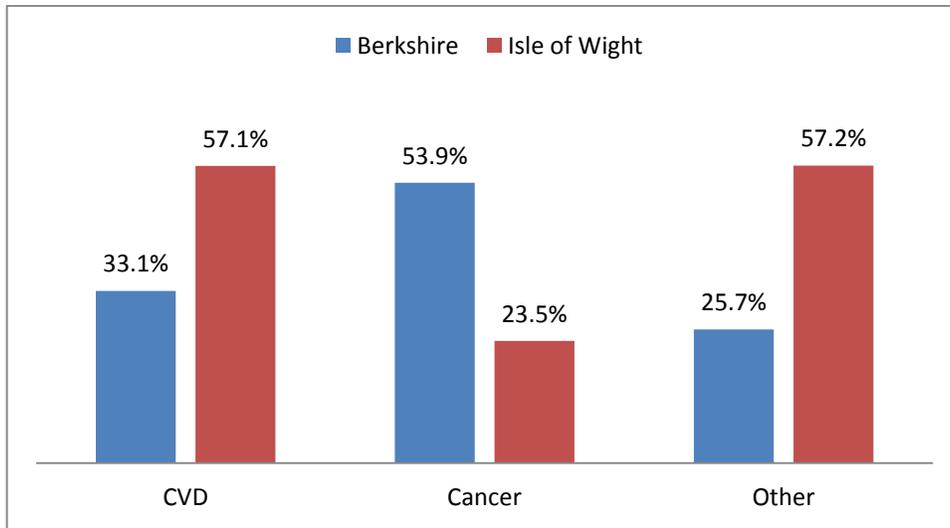
#### Findings by PCT

A slightly greater proportion of patients in the Isle of Wight received excellent pain relief in the last two days (Table 9.15). ‘Poor’ ratings were higher in the Isle of Wight.

### Findings by PCT and cause of death

Unlike for many of the other questionnaire items, relief of pain in the last two days varied considerably between PCTs when stratified by cause of death. For instance, only 23.5% of respondents whose relative died of cancer reported that pain relief was 'excellent' in the last two days whilst in Berkshire East, 53.9% strongly agreed.

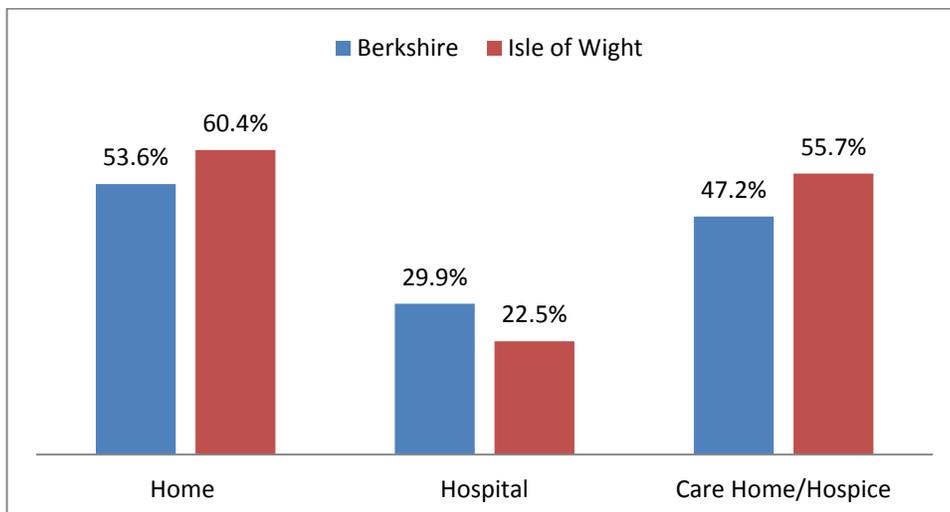
**Figure 9.14: Percentage reporting that pain relief was excellent in the last two days, stratified by cause of death**



### Findings by PCT and place of death

Again, hospitals were the least likely to score highly whilst the home care setting was most highly rated for pain relief, with similar patterns across the PCTs (Figure 9.15).

**Figure 9.15: Percentage reporting that pain relief was excellent in the last two days, stratified by place of death**



### **Qualitative comments**

*“In the last few hours of his life, the care was good. I was very impressed with the palliative care team who took every care to make him comfortable and pain free.” (Berkshire East)*

*“When he was taken into hospital for the last time, it took until I broke down to get adequate pain relief for him. In the last week of his life me and the rest of the family had to watch as he was screaming out in pain because no one would make the decision to give him adequate pain relief.” (Isle of Wight)*

## **v. Relief of symptoms other than pain**

During the last two days, how do you rate the overall level of support given in the following areas from those caring for him/her?

– Relief of symptoms other than pain

Excellent

Good

Fair

Poor

### **Overall findings**

Relief of symptoms other than pain was reported similarly to pain relief with 76.0% reporting excellent or good relief of symptoms in the last two days (Table 9.15).

### **Findings by PCT**

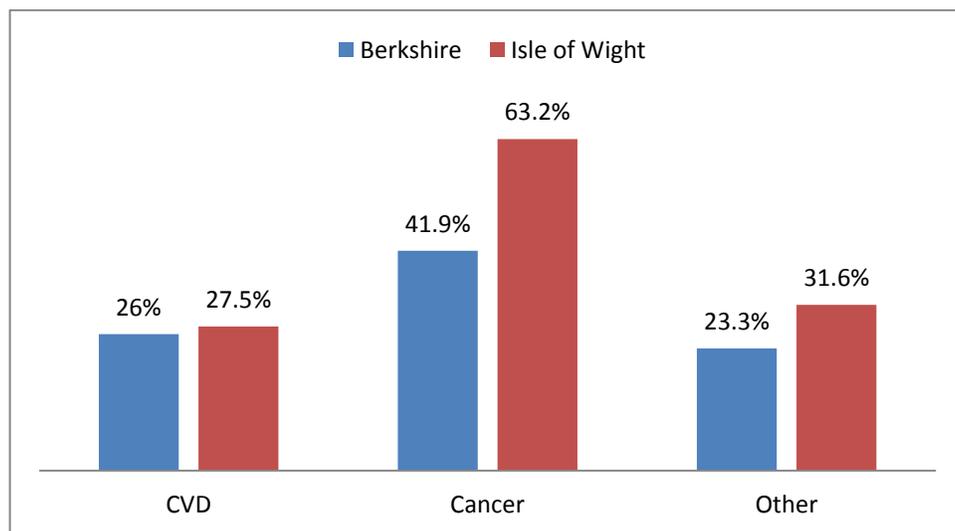
The Isle of Wight scored more highly than Berkshire East for this domain and also had a slightly smaller proportion of respondents rating relief of other symptoms as ‘poor’ (Table 9.15).

### **Findings by PCT and cause of death**

When stratified by cause of death, the pattern of scores between the two PCTs was similar.

Respondents whose relative died of cancer were considerably more likely to report that symptom relief was excellent and in the Isle of Wight as many as 63.2% reported as such.

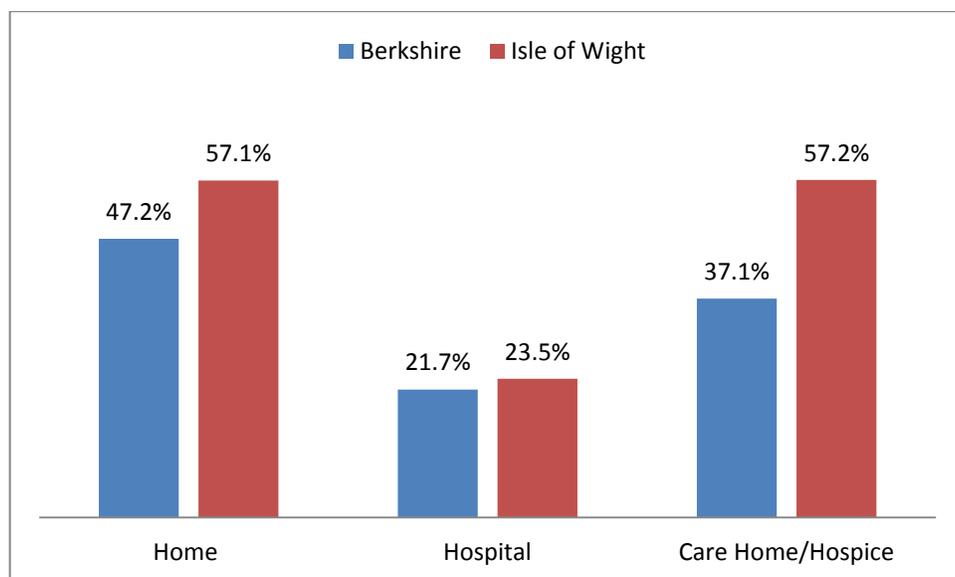
**Figure 9.16: Percentage reporting that relief of other symptoms was excellent in the last two days, stratified by cause of death**



### **Findings by PCT and place of death**

As is the pattern across most domains, hospital care was rated the least favourably, in both PCTs (Figure 9.17).

**Figure 9.17: Percentage reporting that relief of other symptoms was excellent in the last two days, stratified by place of death**



### **Qualitative comments**

Three respondents were unhappy about the quality of symptom relief in the last two days of life.

*“Because she died on a Friday night, there were not enough doctors available... My wife needed an injection to ease her suffering in the last hours of her life. The doctor was called at about 10.30pm, and constantly after, to have the drug administered. I was told this would be priority and a special code was given as it meant the death was imminent. They told the nurse that called on my behalf that they were too busy to come. We called several times through the evening as still no one had come. We were then told that they would send an emergency on-call nurse to administer the injection. They never arrived. My wife died in distress and discomfort.”*

(Anonymous return)

## vi. Spiritual Support

During the last two days, how do you rate the overall level of support given in the following areas from those caring for him/her?

– Spiritual support

Excellent

Good

Fair

Poor

### Overall findings

Spiritual support was rated as excellent by 34.9% of responders. However, 19.7% reported a 'poor' level of support in that area (Table 9.15).

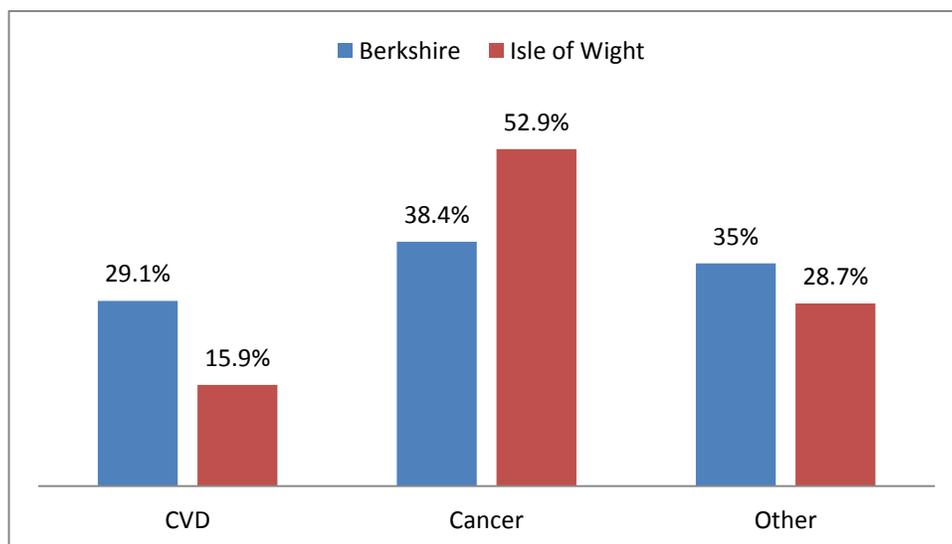
### Findings by PCT

There was very little variation between PCTs for spiritual support in the last two days (Table 9.15).

### Findings by PCT and cause of death

Cancer patients were more likely to receive excellent spiritual support than patients with other conditions, including CVD (Figure 9.18).

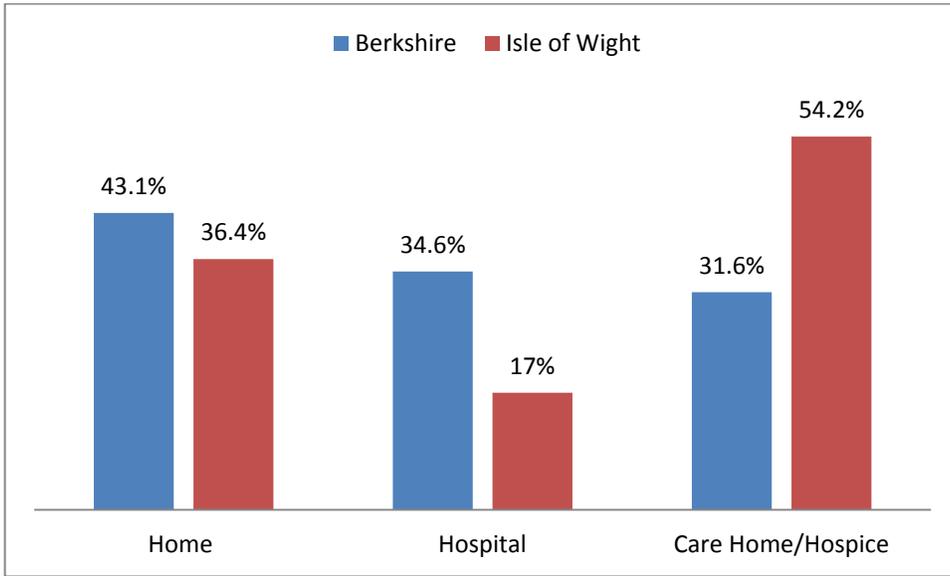
**Figure 9.18: Percentage reporting that spiritual support was excellent in the last two days, stratified by cause of death**



### Findings by PCT and place of death

Spiritual care in care homes and hospices was rated highly in the Isle of Wight but not in Berkshire East. Again, hospitals scored poorly in both PCTs (Figure 9.19).

**Figure 9.19: Percentage reporting that spiritual support was excellent in the last two days, stratified by place of death**



### Qualitative comments

*“They [the nursing staff] arranged everything – a priest, a side room and a private room for the last few days. They thought of everything.”* (Berkshire East)

## vii. Emotional Support

During the last two days, how do you rate the overall level of support given in the following areas from those caring for him/her?

– Emotional support

Excellent

Good

Fair

Poor

### Overall findings

Across the sample, 37.9% of patients were given excellent emotional support in the last two days. 13.6% were given poor support (Table 9.15).

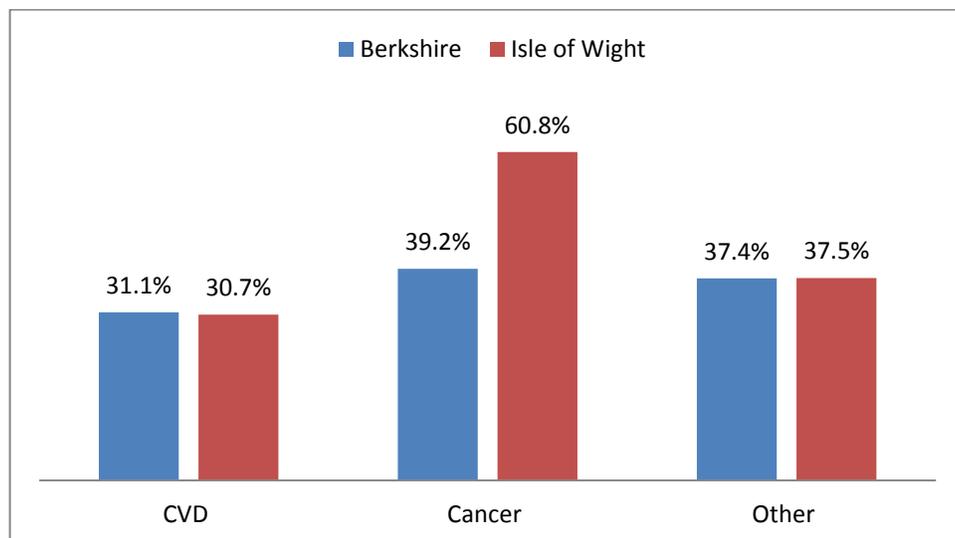
### Findings by PCT

Ratings for emotional support were slightly higher among Isle of Wight informants (Table 9.15).

### Findings by PCT and cause of death

Emotional support for cancer patients in the Isle of Wight was more likely to be rated as excellent than for those who died of any other condition, in either PCT (Figure 9.20).

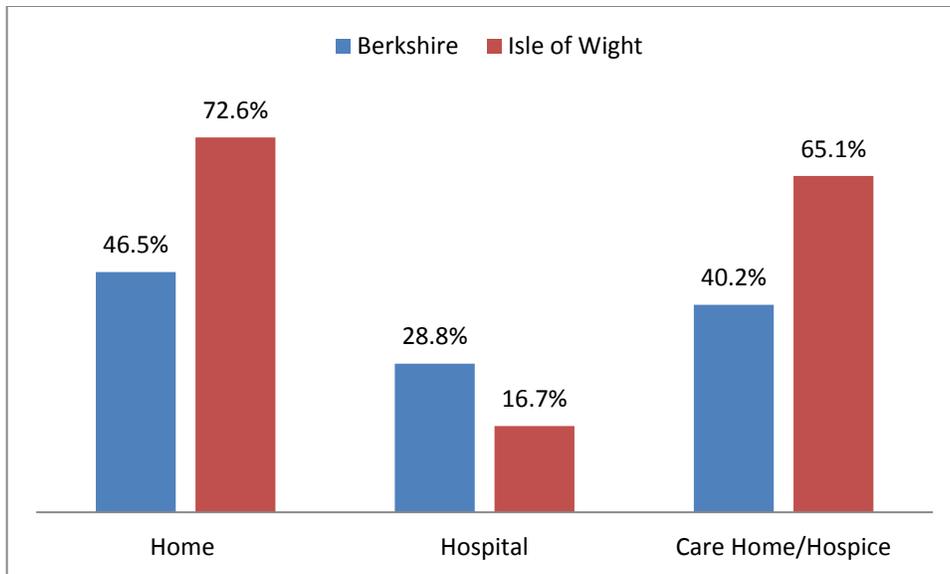
**Figure 9.20: Percentage reporting that emotional support was excellent in the last two days, stratified by cause of death**



### Findings by PCT and place of death

Emotional support for those who died at home or in a care home/hospice was generally rated more highly than for those who died in hospital. With the exception of hospital care, the Isle of Wight fared better on this item (Figure 9.21).

**Figure 9.21: Percentage reporting that emotional support was excellent in the last two days, stratified by place of death**



### Qualitative comments

*“Thank goodness his last days were filled with love and care from all staff and ourselves as a family and we were able to be with him night and day. Our hospice is a very special place.”*  
(Isle of Wight)

*“On the night before she died someone held her hand all through the night and talked to her even though she was not conscious and we were summoned to be with her in the last hour of her life, so that she was not alone. I can honestly say that the nursing staff at [nursing home] are to be highly commended on the level of care given to my mother in the last months of her life and the warmth and care they extended to us was incredible. We were very lucky to have such support and care for my mother and us as a family extended to us by these people.”*  
(Berkshire East)

### viii. Support to stay where s/he wanted to be

During the last two days, how do you rate the overall level of support given in the following areas from those caring for him/her?

– Support to stay where s/he wanted to be

Excellent

Good

Fair

Poor

#### Overall findings

48.8% of respondents reported excellent support to allow patients to remain where they wanted to be in the last two days of life. 11.1% reported a poor level of support in this area (Table 9.15).

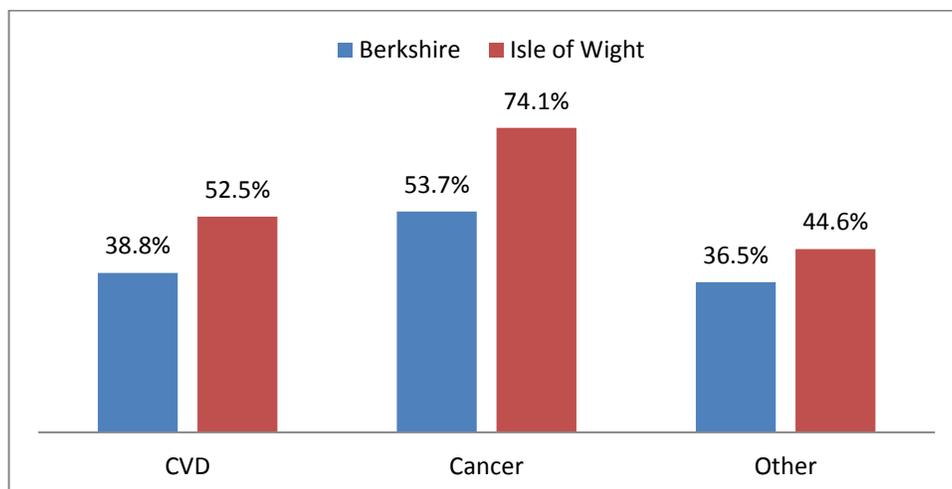
#### Findings by PCT

The Isle of Wight scored more highly on this questionnaire item and the proportion of respondents in Berkshire East reporting that this support was ‘poor’ was double that of the Isle of Wight (Table 9.15).

#### Findings by PCT and cause of death

Again, out of all conditions, cancer patients were most supported to stay where they wished in the last two days of life, particularly in the Isle of Wight (Figure 9.22).

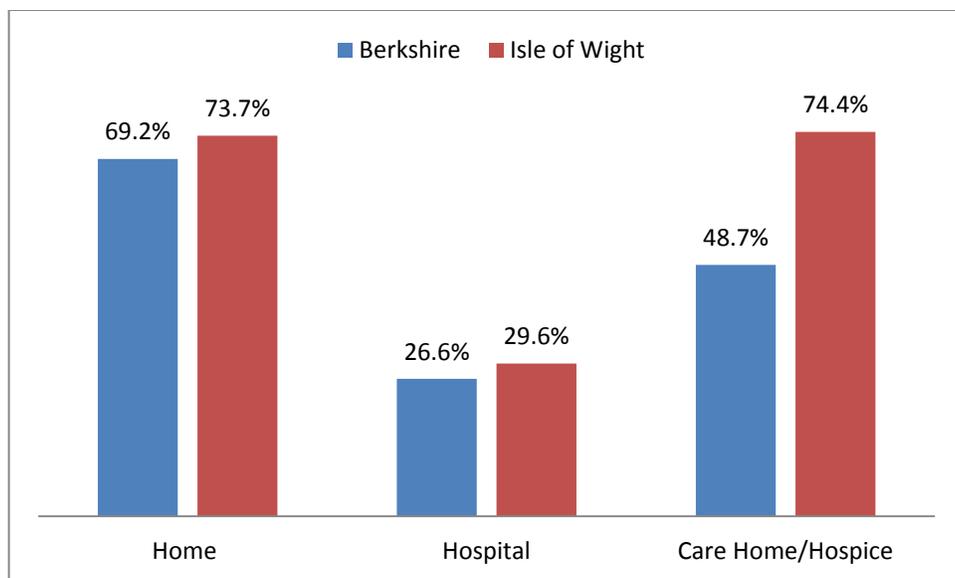
**Figure 9.22: Percentage reporting that support to stay where the patient preferred was excellent in the last two days, stratified by cause of death**



### Findings by PCT and place of death

Respondents whose relative died in hospital (in both PCTs) were the least likely to report excellent support to allow them to stay where they wished in the last two days of life. As is visible in Figure 9.23, other care settings scored much more favourably on this questionnaire item.

**Figure 9.23: Percentage reporting that support to stay where the patient preferred was excellent in the last two days, stratified by place of death**



### 9.8.7. The patient's needs and preferences

Although there is considerable overlap between 'patient needs and preferences' and 'Preferred Priorities for Care', the two concepts are discussed separately in this Report. We describe 'Patient needs and preferences' using questionnaire items that address:

- Whether any decisions were made that the patient would not have wanted
- Whether the patient was involved in their care as much as they would have wanted
- Whether the person who told them they were going to die did so in a sensitive and caring way

Were there any decisions made about his/her care or treatment that s/he would not have wanted?

Yes

No

#### Overall findings and by PCT

The vast majority of respondents reported that no decisions were made about their relative's care that they would not have wanted (76.3%) and this was similar across the PCTs (Table 9.16).

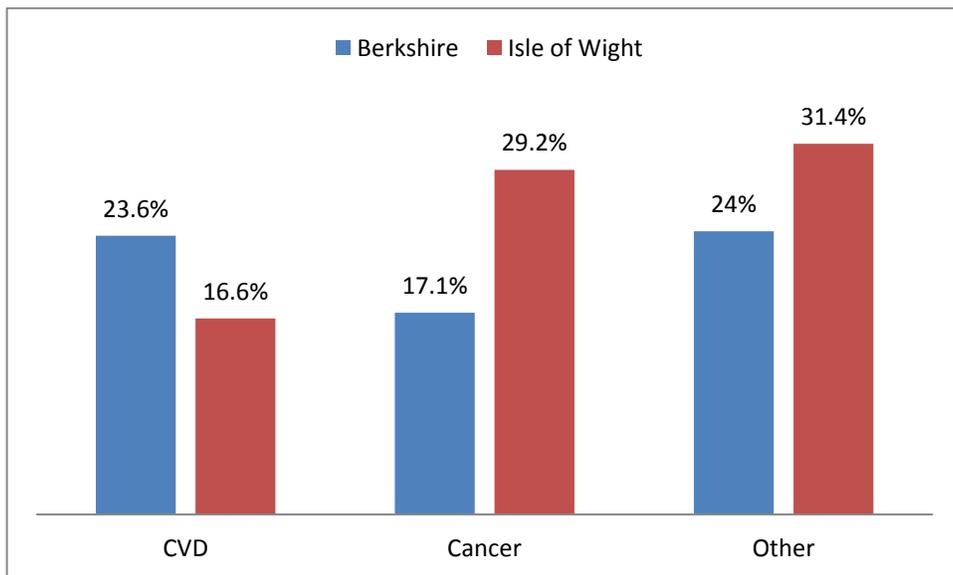
**Table 9.16: Whether there were any decisions made that the patient would not have wanted (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
Yes	23.7 (236.8)	21.8 (129.6)	26.5 (107.2)
No	76.3 (762.2)	78.2 (465.0)	73.5 (297.2)

#### Findings by PCT and cause of death

Relatives of CVD patients in the Isle of Wight were the least likely to report that decisions were made that the patient would not have wanted (Figure 9.24) whilst those who died of 'other' causes were the most likely (31.4%).

**Figure 9.24: Percentage reporting that decisions were made that the patient would not have wanted, stratified by cause of death**



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

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

### Overall findings and by PCT

82.9% of respondents reported that their relative was involved in their own care as much as they would have wanted and this was similar in both PCTs (Table 9.17).

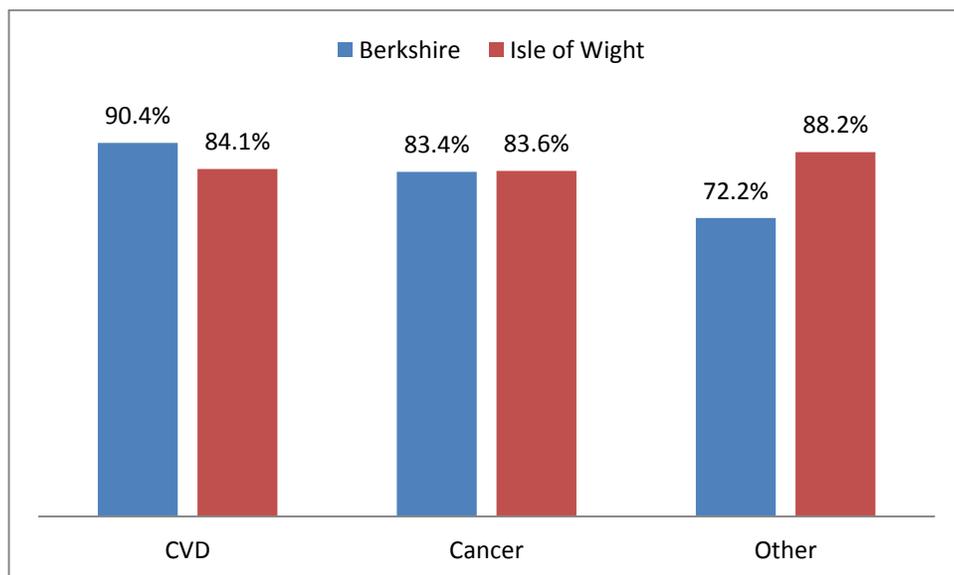
**Table 9.17: Whether the patient was involved in decisions about their care as much as they would have wanted (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
S/he was involved as much as she wanted to be	82.9 (892.9)	81.3 (531.1)	85.5 (361.7)
S/he would have liked to be more involved	16.3 (176.0)	17.9 (116.9)	14.0 (59.1)
S/he would have liked to be less involved	0.7 (7.9)	0.8 (5.6)	0.6 (2.4)

### Findings by PCT and cause of death

Across PCTs and the three cause of death classifications, there was very little variation in the proportion reporting that patients were involved as much as they would have wanted (Figure 9.25).

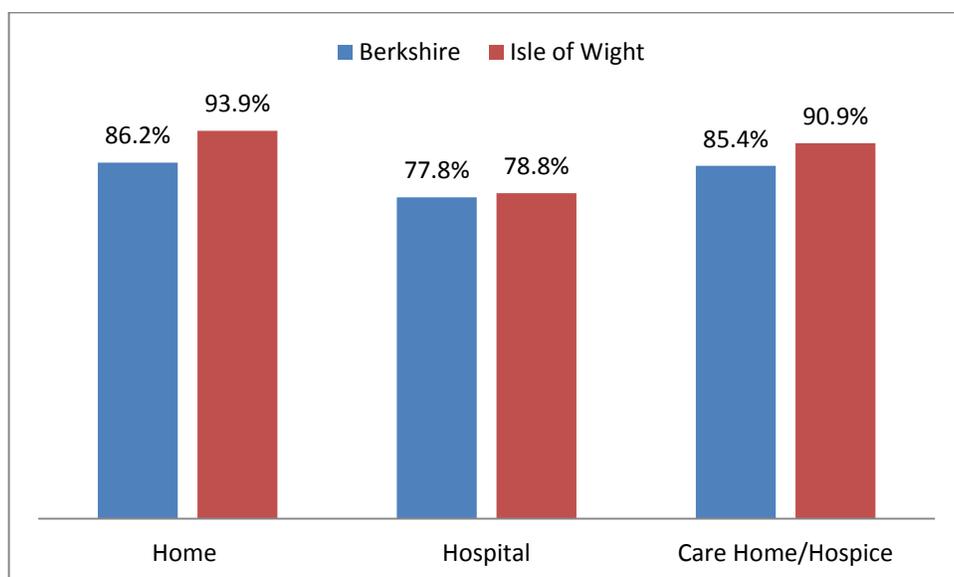
**Figure 9.25: Percentage reporting that the patient was involved in their care as much as they would have wanted, stratified by cause of death**



**Findings by PCT and place of death**

As for the cause of death sub-analyses, for place of death there was very little variation in the proportion reporting that patients were involved as much as they would have wanted (Figure 9.26).

**Figure 9.26: Percentage reporting that patients were as involved in their care as much as they would have wanted, stratified by place of death**



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

Yes, definitely

Yes, to some extent

No, not at all

### Overall findings and by PCT

11.5% of respondents reported that when their relative was told that they were dying, it was not done in a caring and sensitive way (Table 9.18).

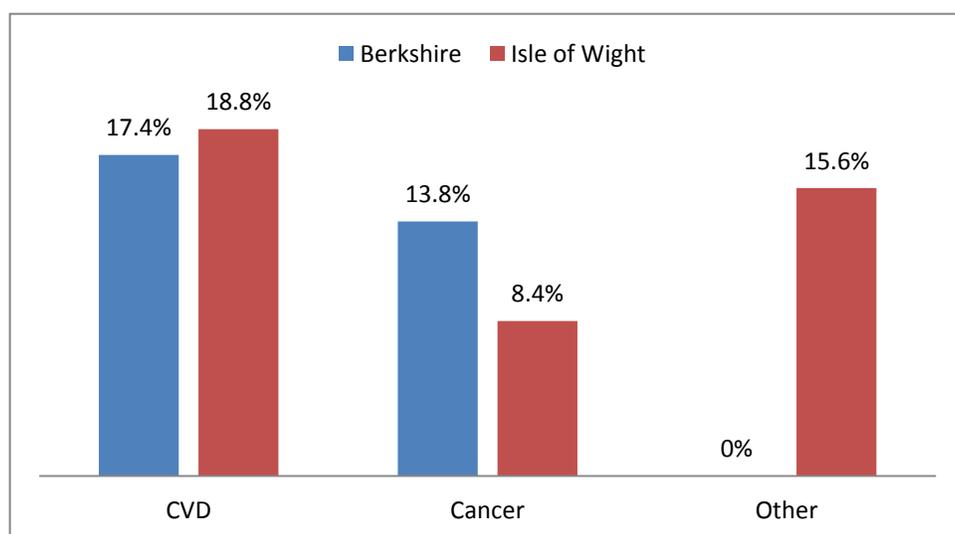
**Table 9.18: Whether bad news was delivered in a sensitive manner (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
Yes, definitely	54.9 (208.5)	49.0 (118.8)	65.4 (89.6)
Yes, to some extent	33.6 (127.6)	39.5 (95.9)	23.1 (31.7)
No, not at all	11.5 (43.7)	11.5 (28.0)	11.5 (15.7)

### Findings by PCT and cause of death

In both PCTs, more than 1 in 10 CVD patients were not told that they were going to die in a caring way (Figure 9.27). Note that although a high proportion of ‘other’ patients in Isle of Wight reported insensitivity, the numbers in the analysis are very small.

**Figure 9.27: Percentage reporting that the clinician who informed the patient that they were going to die, did not do so in a caring and sensitive way, stratified by cause of death**



### 9.8.8. Preferred Priorities for Care

Seven questionnaire items directly refer to Preferred Priorities for Care and preferences for place of death. The findings of these items are discussed below.

Did s/he know s/he was likely to die?

- Yes
- Yes probably
- Probably not
- No definitely

#### Overall findings

A relatively small proportion of patients were aware that they were going to die although a further 30.9% of respondents reported that they thought their relative ‘probably’ knew they were going to die (Table 9.19).

**Table 9.19: Whether the patient knew they were going to die (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
Yes, certainly	39.0 (453.8)	36.8 (257.3)	42.4 (196.5)
Yes, probably	30.8 (358.5)	30.8 (214.9)	30.9 (143.5)
Probably not	19.0 (220.8)	22.2 (155.0)	14.2 (65.8)
No, definitely	11.2 (120.7)	10.2 (71.6)	12.5 (58.1)

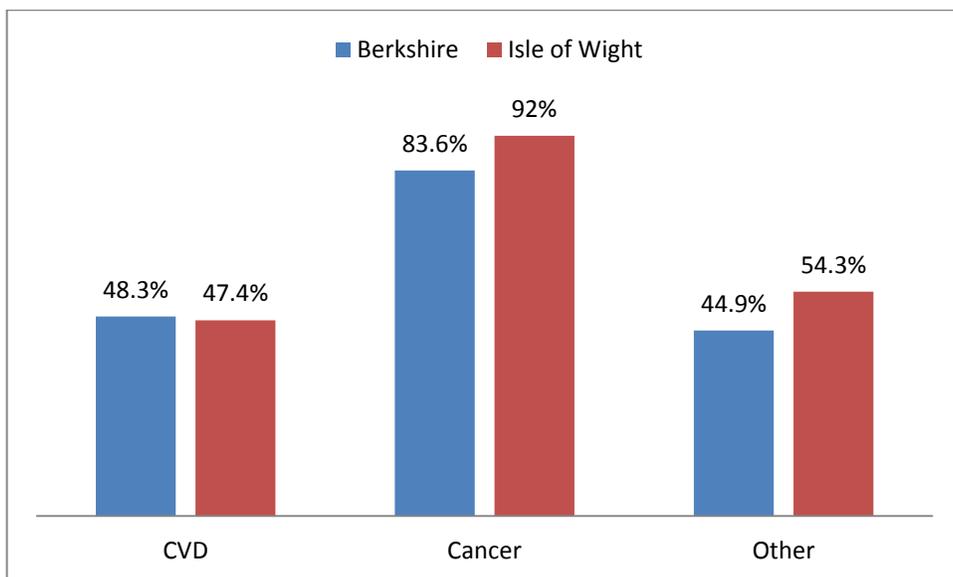
#### Findings by PCT

A greater proportion of patients in the Isle of Wight were aware that they were going to die or were ‘probably’ aware that they were going to die than in Berkshire East (Table 9.19).

#### Findings by PCT and cause of death

For the purposes of these sub-analyses and as a result of the ensuing small number of participants in each category, the two response options ‘Yes’ and ‘Yes, probably’ were collapsed into one category. As might be expected, cancer patients were more likely to be aware that they were dying than patients with other conditions. As might also be expected, there were few between-PCT differences.

**Figure 9.28: Percentage of patients aware they were going to die, stratified by cause of death**



Where did s/he die?

In own home

In someone else's home

In a hospital ward

In a hospital ICU

In a hospice

In a care home

Somewhere else

### Overall findings and by PCT

As displayed in Table 9.20, the majority of patients died in a hospital ward, followed by a care home. The proportion of patients dying in a care home was slightly higher in the Isle of Wight than in Berkshire East which may account for the fewer hospital deaths in the Isle of Wight.

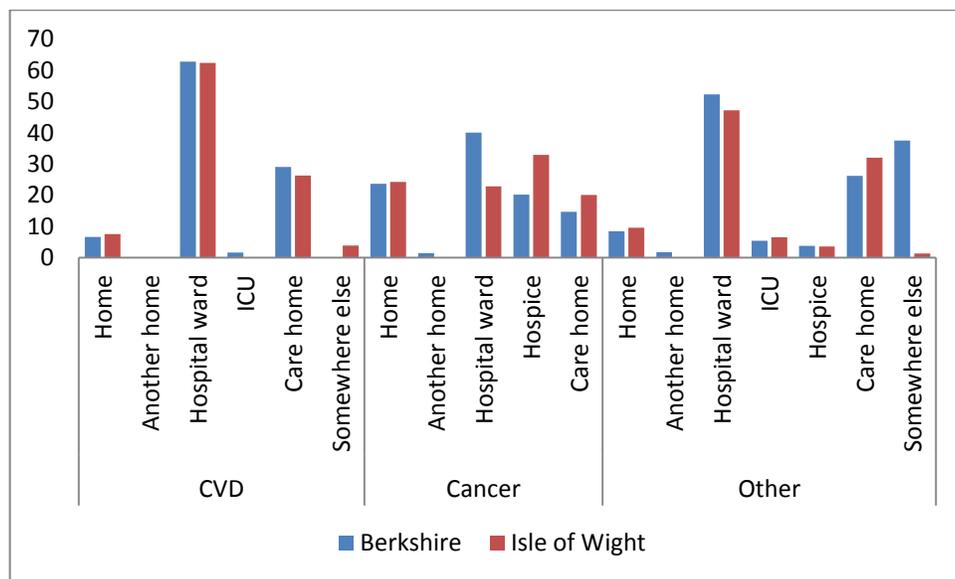
**Table 9.20: Place of death in both PCTs**

Place of Death	Berkshire East (%)	Isle of Wight (%)	Total (%)
In own home	13.6 (105.4)	13.2 (67.7)	13.5 (173.1)
In someone else's home	1.2 (8.9)	0 (0)	0.7 (9.0)
In a hospital ward	50.1 (387.8)	44.2 (226.4)	47.8 (614.2)
In a hospital ICU	2.5 (19.2)	2.9 (14.7)	2.6 (34.0)
In a hospice	9.1 (70.3)	11.2 (57.2)	9.9 (127.5)
In a care home	22.6 (174.6)	27.0 (138.7)	24.4 (313.3)
Somewhere else	0.9 (7.3)	1.5 (7.9)	1.2 (15.3)

### Findings by PCT and cause of death

There were some differences in the pattern of place of death when stratified by cause of death. For instance, CVD patients were much more likely to die in hospital than in any other care setting and this was consistent across the PCTs. As might be anticipated, cancer patients were more likely than other patients to die in a hospice although the proportion was higher in the Isle of Wight than in Berkshire East. No cancer patients died in the ICU, in either PCT (Figure 9.29).

Figure 9.29: Place of death, stratified by cause of death



Did s/he ever say where s/he would like to die?

Yes

No

Not sure

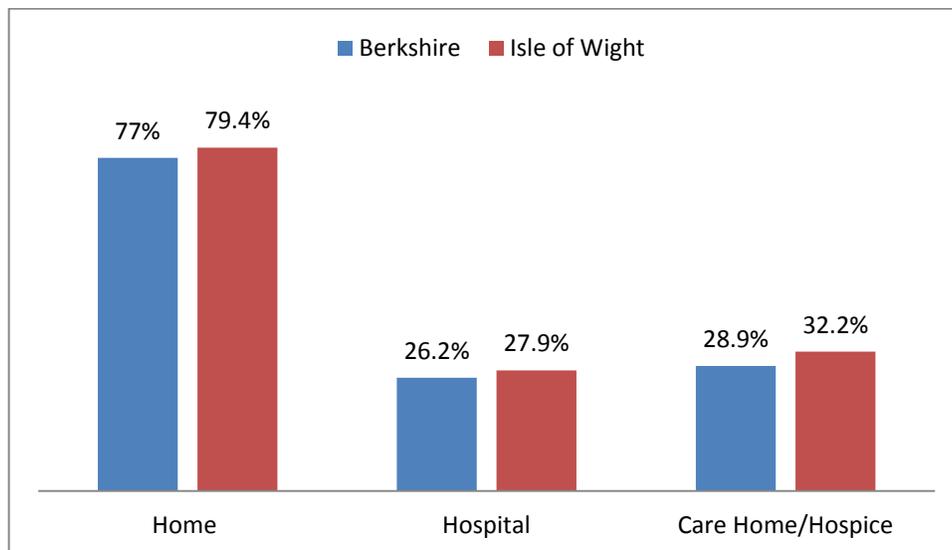
The minority of patients expressed where they would like to die (35.4%) and this was similar across the PCTs (34.9% in Berkshire East compared to 36.1% in the Isle of Wight).

### Findings by PCT and place of death

When looking at these data stratified by place of death, the data suggest an association between dying at home and having a preference about place of death (Figure 9.30). For instance, 77.0% of those who died at home in Berkshire East said where they would like to die (79.4% in the Isle of Wight).

Conversely, a much smaller percentage of patients who died in hospital had said where they wanted to die.

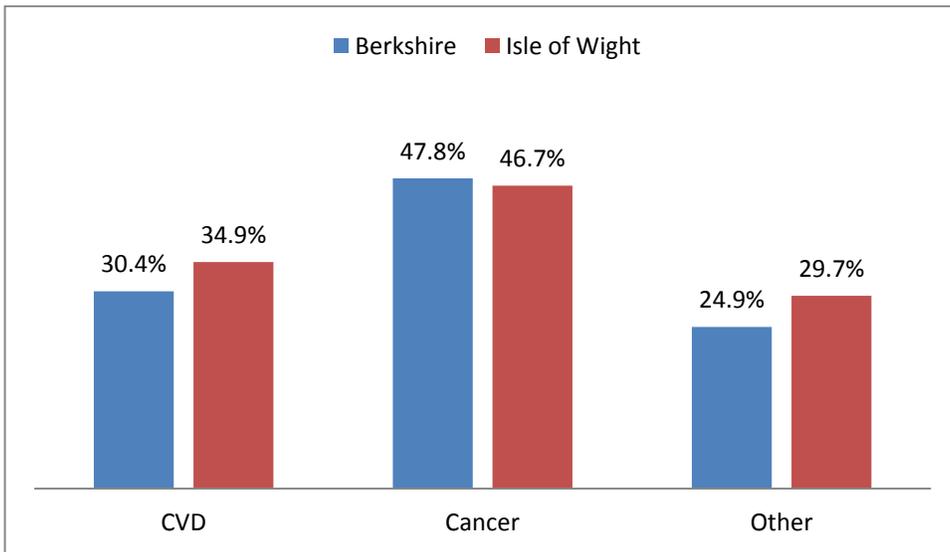
**Figure 9.30: Percentage of patients saying where they would like to die, stratified by place of death**



### Findings by PCT and cause of death

A greater proportion of cancer patients expressed where they would like to die than CVD patients or those who died of other causes, and this was apparent in both PCTs (Figure 9.31).

**Figure 9.31: Percentage of patients saying where they would like to die, stratified by cause of death**



Where did she say s/he would like to die?

At home

In a hospice

In a hospital

In a care home

S/he said s/he did not mind where he/she died

S/he changed his/her mind about where s/he wanted to die

Somewhere else

### Overall findings

Most patients had expressed a wish to die at home and only 1% had changed their mind about where they wanted to die (Table 9.21).

**Table 9.21: Preferred place of death (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
<b>At home</b>	67.7 (314.8)	65.8 (184.0)	70.7 (130.9)
<b>In a hospice</b>	9.1 (42.5)	9.9 (27.6)	8.1 (14.9)
<b>In a hospital</b>	4.4 (20.5)	6.0 (16.9)	2.0 (3.6)
<b>In a care home</b>	6.5 (30.3)	5.0 (14.0)	8.8 (16.3)
<b>He said he did not mind where he died</b>	8.4 (39.0)	9.4 (26.2)	6.9 (12.8)
<b>He changed his mind about where he wanted to die</b>	1.0 (4.4)	0.9 (2.6)	1.0 (1.8)
<b>Somewhere else</b>	2.9 (13.4)	3.0 (8.5)	2.6 (4.9)

### Findings by PCT

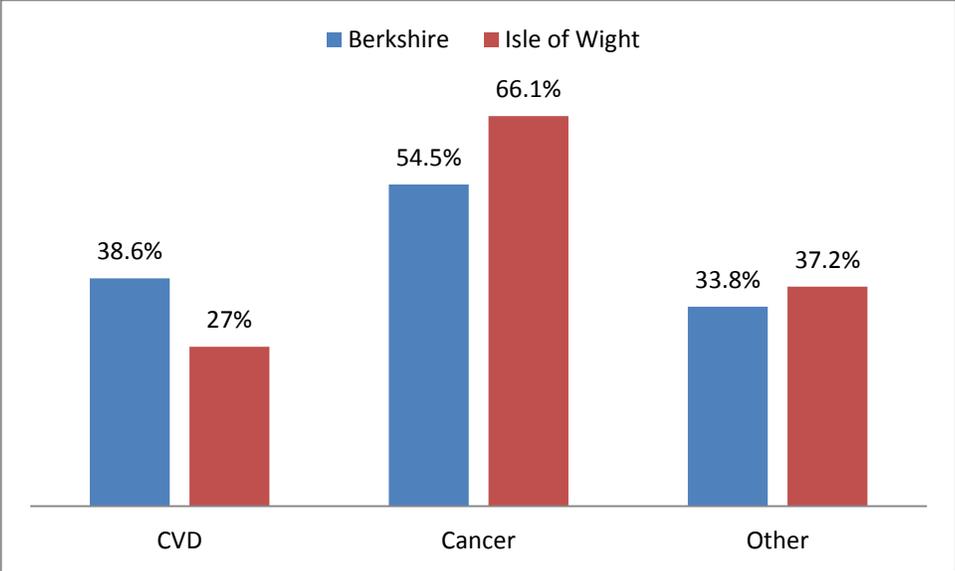
The findings were similar across the PCTs although a slightly higher proportion of Isle of Wight patients expressed a wish to die at home than Berkshire East patients (Table 9.21). This difference was largely accounted for by the increased proportion of those wishing to die in hospital in Berkshire East.

### Preferred place of death and actual place of death

Across the PCTs, 44.6% of patients who said where they would like to die, died in their preferred place. This was very similar in each PCT (44.8% in Berkshire East and 44.2% in the Isle of Wight). When looking at whether patients died where they wanted, stratified by cause of death, a more complex picture emerges. Cancer patients were more likely to die in their preferred place than those who died from any other condition (58.2% compared to 34.0% of CVD patients and 35.5% of patients who died of 'other')

causes). CVD patients in the Isle of Wight were the least likely to die in the place they wished (Figure 9.32).

**Figure 9.32: Percentage of patients who died where they wanted to die, stratified by cause of death**



Did the healthcare staff have a record of this?

Yes

No

Not sure

### Overall findings

For this questionnaire item, a large proportion of respondents were unsure whether the healthcare staff had a record of their relative's preferences about place of death (36.1%) and so it is possible that these data underestimate the true proportion. However, in 36.1% of cases, the respondents were aware that staff did have a record whilst the remaining 26.9% reported that staff did not have a record of preferences.

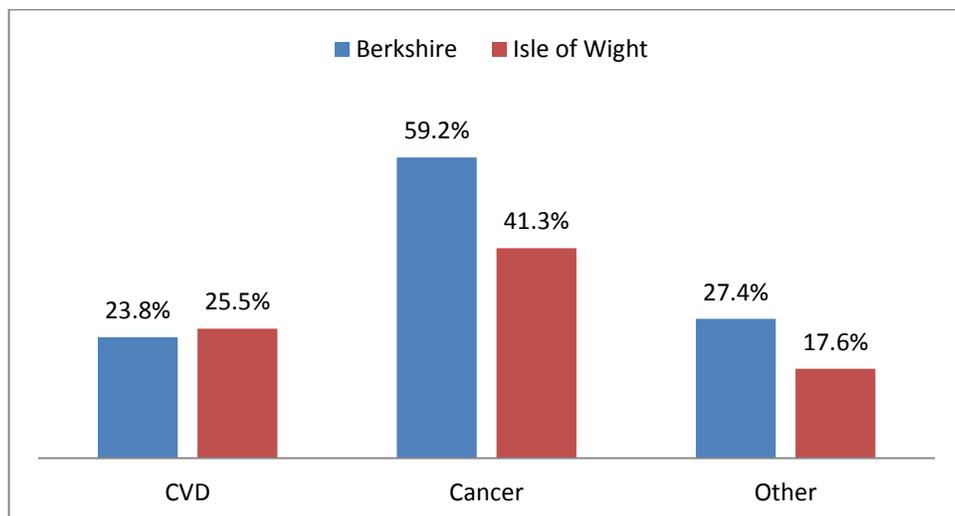
### Findings by PCT

Between-PCT differences were quite marked. In Berkshire East, a record of preferences for place of death was present for 41.7% of patients whilst in the Isle of Wight, this was only the case for 28.2% of patients.

### Findings by PCT and cause of death

Overall, cancer patients were most likely to have a record of their preferences (Figure 9.33) and in Berkshire East, a record of preferences was present in 59.2% of cancer patients. Patients who died of 'other causes' in the Isle of Wight were the least likely to have a record of their preferences for end of life care (17.6%).

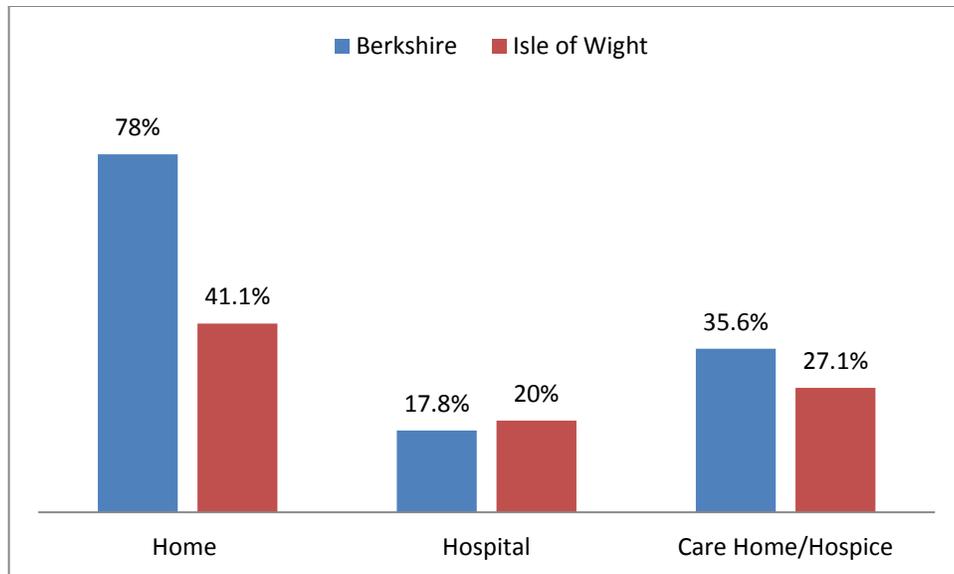
**Figure 9.33: Percentage of cases where healthcare staff had a record of place of death preferences, stratified by cause of death**



### Findings by PCT and place of death

Patients who died at home were more likely to have an official record of their preferences than those who died in other care settings (Figure 9.34). This was particularly the case for those who died at home in Berkshire East (78%).

**Figure 9.34: Percentage of cases where healthcare staff had a record of place of death preferences, stratified by cause of death**



Do you think s/he had enough choice about where s/he died?

Yes

No

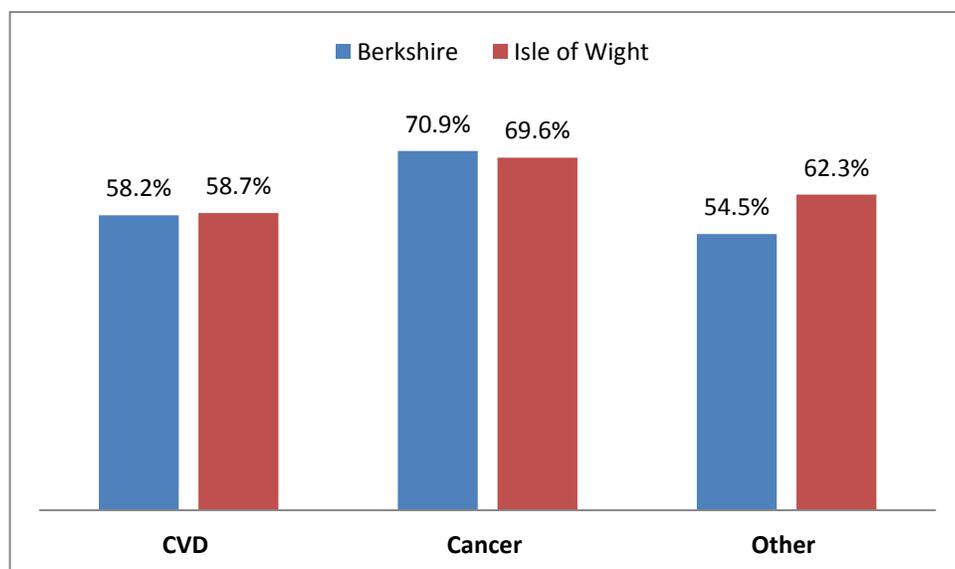
### Overall findings

62.0% of informants reported that their relative had enough choice about where they died and this was comparable between PCTs (62.3% in Berkshire East, 61.6% in the Isle of Wight).

### Findings by PCT and cause of death

Across both PCTs, cancer patients were more likely to have had enough choice about where they died than those who died of CVD or other causes. There were no marked PCT differences (Figure 9.35).

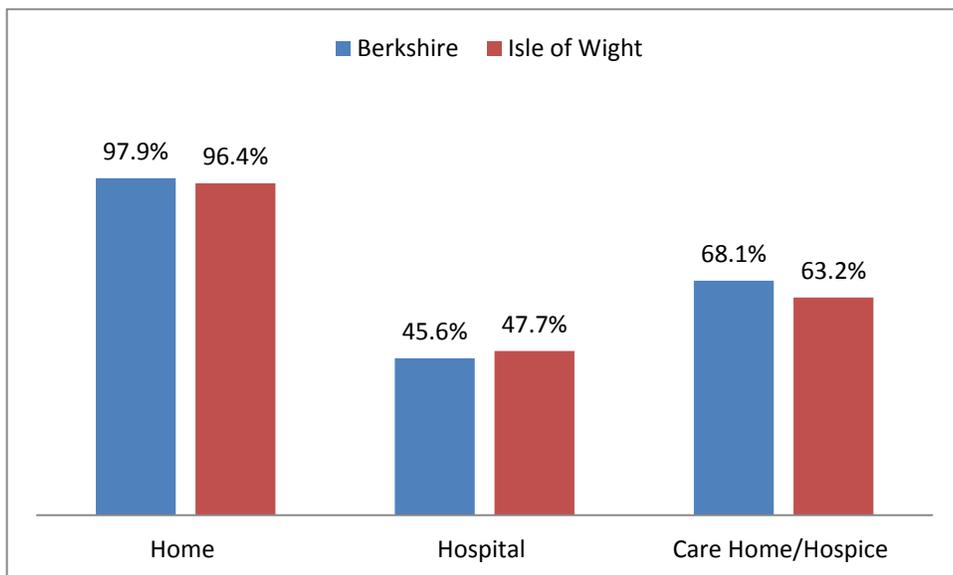
**Figure 9.35: Percentage reporting enough choice about place of death, stratified by cause of death**



### Findings by PCT and place of death

Those who died at home were much more likely to have been given enough choice about where they died than those who died in hospital (Figure 9.36).

**Figure 9.36: Percentage reporting enough choice about place of death, stratified by place of death**



On balance, do you feel s/he died in the right place?

Yes

No

Not sure

### Overall findings

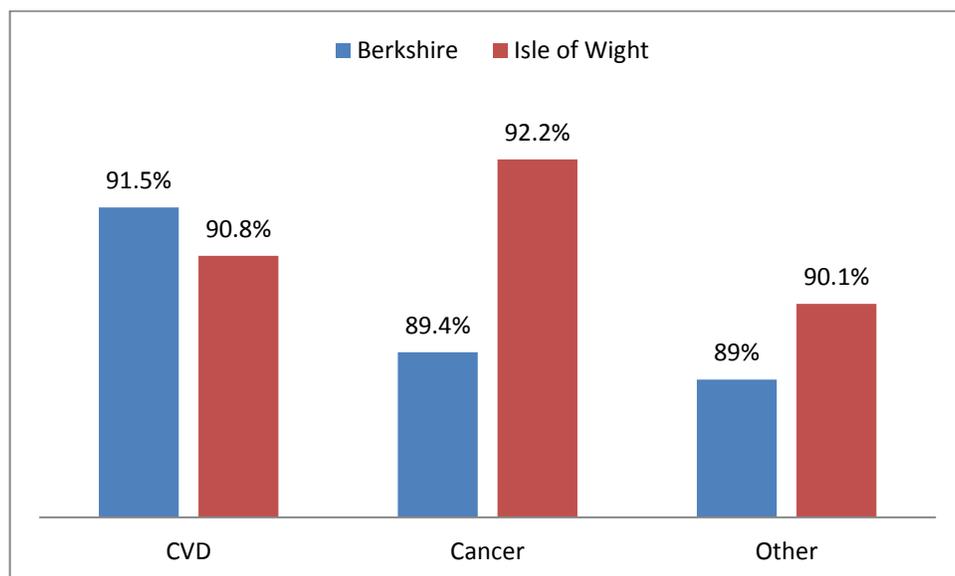
The overwhelming majority of respondents felt that their relative died in the right place (90.2%) and this was consistent across the two PCTs (89.7% in Berkshire East and 90.9% in the Isle of Wight).

### Findings by PCT and cause or place of death

When looking at this item stratified by place or cause of death there are very few differences given that 90% answered 'yes' to the question. However, it is worth noting that all respondents whose relative died at home reported that they had died in the right place, yet this was only the case for 83.4% of those who died in a hospital (81.4% in Berkshire East and 86.6% in the Isle of Wight).

For cause of death (Figure 9.37), respondents whose relative died of cancer in the Isle of Wight were the most likely to report that their relative died in the correct.

**Figure 9.37: Percentage reporting that their relative died in the right place**



### 9.8.9. Support for Carers

Support for carers was measured using three questionnaire items covering help with home based care, discussing worries and fears with the GP and level of involvement in care. The next section (9.8.10) covers care and support provided to carers after the death of their relative.

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/her?

Yes, we got as much help as we needed

Yes, we got some support but not as much as we needed

No, although we tried to get more help

#### Overall findings

Most informants reported that they received as much support as they wanted. However, 20.9% reported that they did not receive enough help, even though they tried to get more (Table 9.22).

**Table 9.22: Carer support from health and social services (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
Yes, we got as much support as we wanted	53.2 (372.6)	47.5 (207.3)	62.8 (165.4)
Yes, we got some support but not as much as we wanted	25.8 (180.9)	32.3 (141.1)	15.1 (39.8)
No, although we tried to get more help	20.9 (146.5)	20.2 (88.4)	22.1 (58.0)

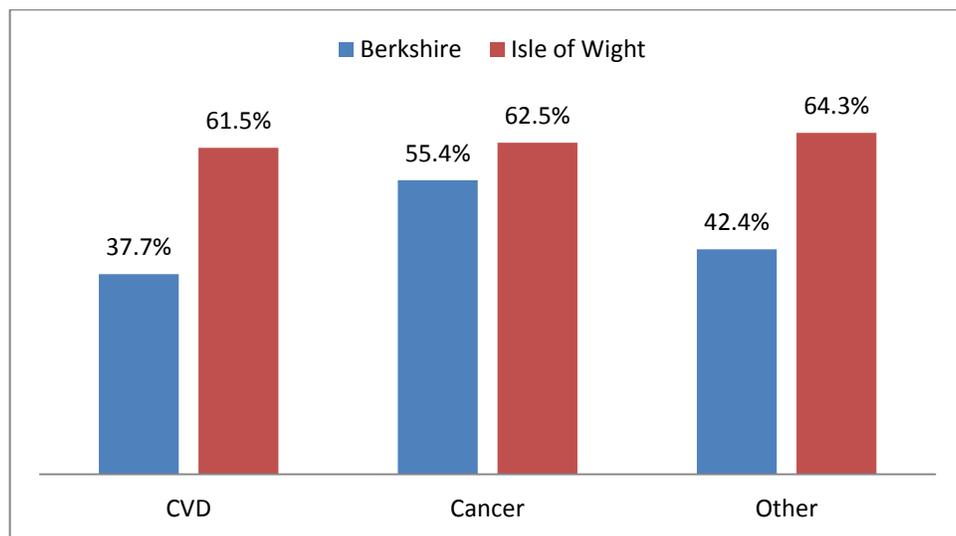
#### Findings by PCT

The Isle of Wight scored more favourably on this domain (Table 9.22).

#### Findings by PCT and cause of death

Although the proportion reporting sufficient support was generally lower in Berkshire East (Figure 9.38), those who died of CVD in Berkshire East were less likely to report sufficient support with home care than in the Isle of Wight (37.7% compared to 61.5%).

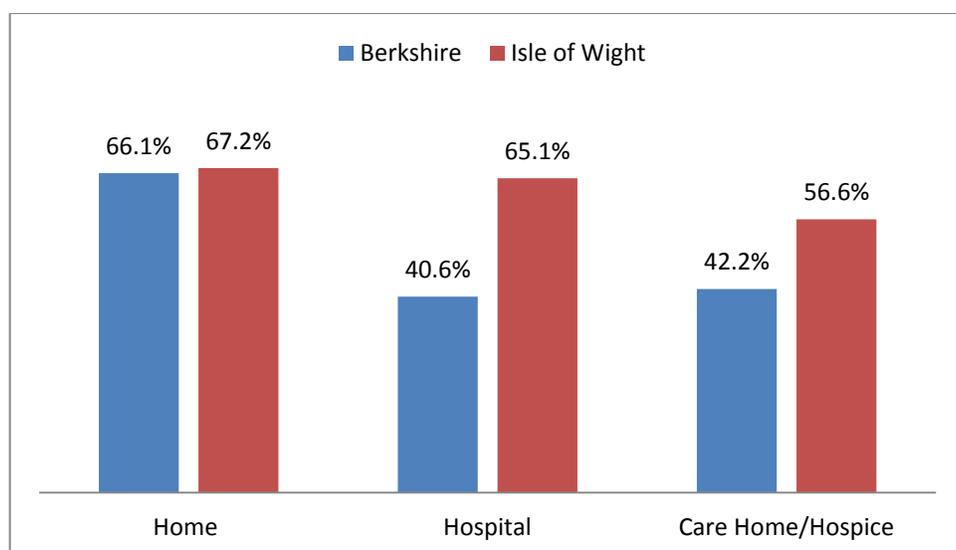
**Figure 9.38: Percentage reporting enough support when caring for relative at home, stratified by cause of death**



### **Findings by PCT and place of death**

Home-based support for carers looking after a relative who died at home was similar in both PCTs (Figure 9.39).

**Figure 9.39: Percentage reporting enough support when caring for relative at home, stratified by place of death**



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

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

### Overall findings

Most informants reported that they were able to discuss worries and fears as much as they wanted. However, 10% reported that although they tried to discuss their worries and fears, such discussions did not take place (Table 9.23).

**Table 9.23: Carers' ability to discuss worries and fears with the GP (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
Yes, I discussed them as much as I wanted	63.8 (464.1)	64.6 (281.5)	62.4 (182.6)
Yes, I discussed them but not as much as I wanted	26.3 (191.3)	26.2 (114.0)	26.4 (77.3)
No, although I tried to discuss them	10.0 (72.5)	9.2 (40.0)	11.1 (32.5)

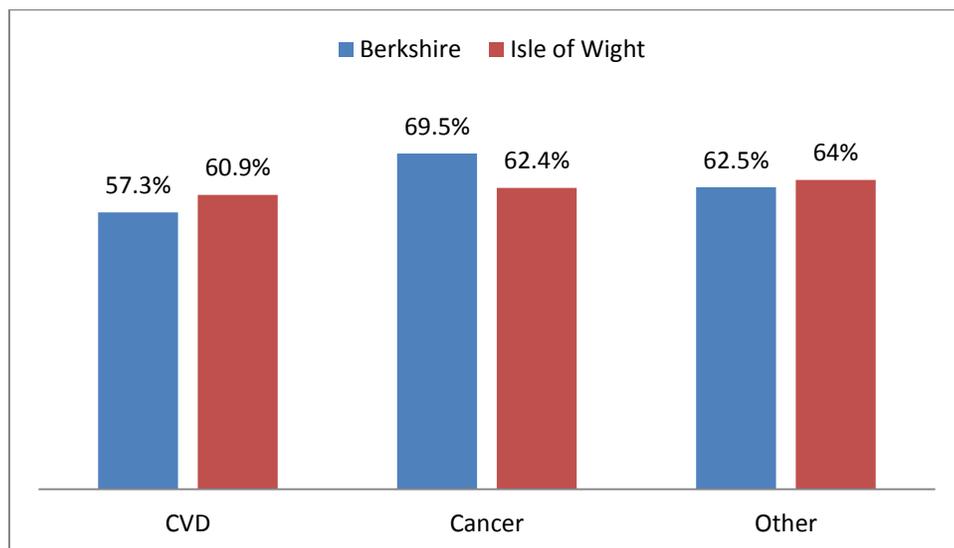
### Findings by PCT

Both PCTs scored similarly on this item (Table 9.23).

### Findings by PCT and cause of death

Informants whose relative died of CVD (in both PCTs) were slightly less likely to report being able to discuss worries and fears with the GP (Figure 9.40).

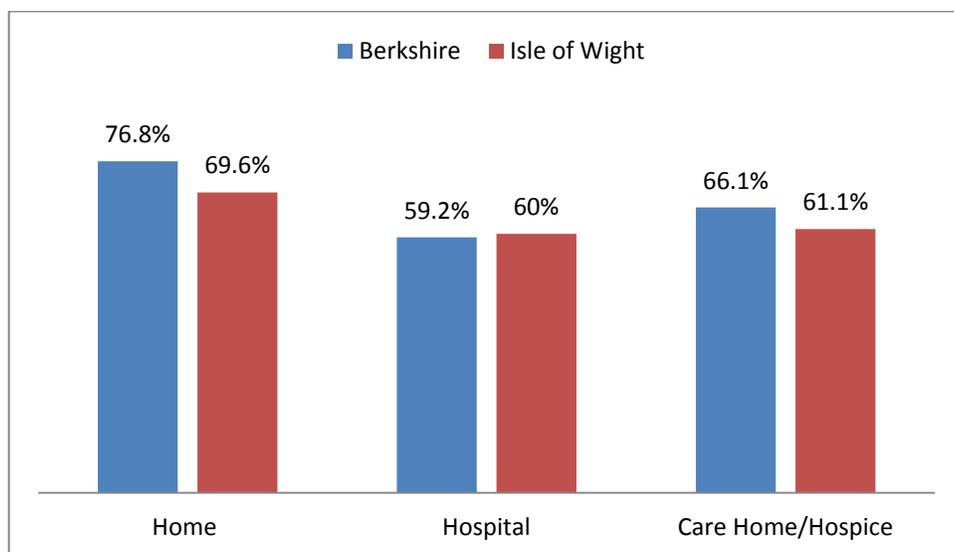
**Figure 9.40: Percentage feeling able to discuss worries and fears with the GP, stratified by cause of death**



### **Findings by PCT and place of death**

There was little variation across PCTs and place of death for this questionnaire item although those who died at home in Berkshire East were most likely to report being able to discuss worries and fears with their GP (Figure 9.41).

**Figure 9.41: Percentage feeling able to discuss worries and fears with the GP, stratified by place of death**



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

I was involved as much as I wanted

I would have liked to be more involved

I would have liked to be less involved

### Overall findings and by PCT

The majority of informants reported that they were involved in decisions about their relative's care as much as they would have wanted and this was similar across the PCTs (Table 9.24).

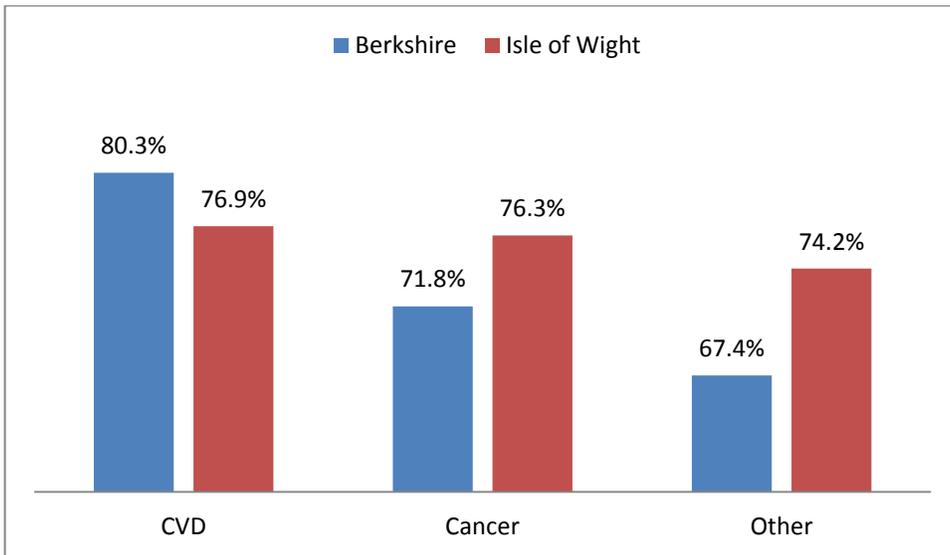
**Table 9.24: Carers' satisfaction with involvement in decisions about care (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
I was involved as much as I wanted to be	73.6 (946.4)	72.2 (559.9)	75.6 (386.6)
I would have liked to be more involved	26.0 (335.1)	27.8 (215.4)	23.4 (119.8)
I would have liked to be less involved	0.4 (5.1)	0 (0)	1.0 (5.1)

### Findings by PCT and cause of death

Relatives of CVD patients in Berkshire East were the most likely to report that they were as involved in the care as much as they would have wanted (80.3%). In the Isle of Wight data there was an even spread of ratings between the three cause of death categories (Figure 9.42).

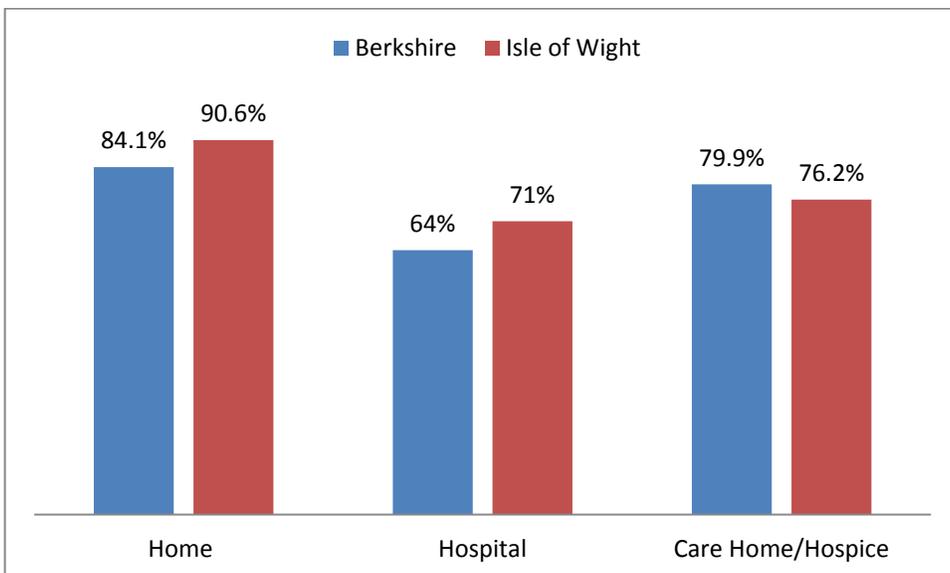
**Figure 9.42: Percentage reporting sufficient involvement in decisions about the care of their relative, stratified by cause of death**



### **Findings by PCT and place of death**

Respondents whose relative died at home were the most likely to report being as involved in their care as much as they wanted. This was the case in both PCTs (Figure 9.43).

**Figure 9.43: Percentage reporting sufficient involvement in decisions about the care of their relative, stratified by place of death**



### 9.8.10. After-death Support

After-death support for carers and relatives was measured using three VOICES questionnaire items that focus on support at the actual time of the death, whether staff were sensitive at that time and whether bereavement services were offered.

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

Yes, definitely

Yes to some extent

No, not at all

#### Overall findings and by PCT

Sixty percent of respondents reported that the staff had provided enough help and support at the actual time of the death of their relative (Table 9.25). Berkshire East scored more favourably than in the Isle of Wight on this item.

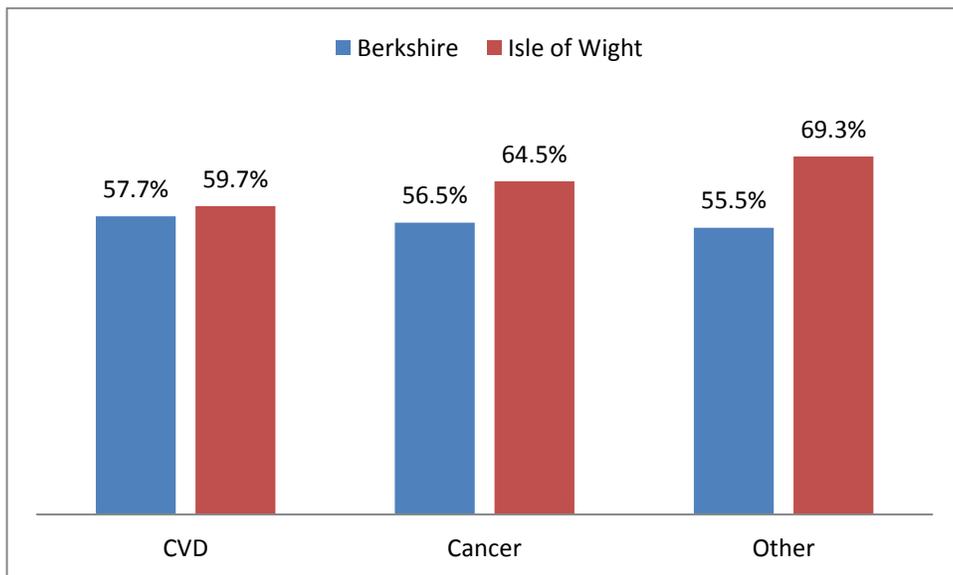
**Table 9.25: Support given to carers at the actual time of the death (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
Yes, definitely	60.2 (749.9)	56.5 (422.0)	65.7 (327.9)
Yes, to some extent	25.8 (322.2)	26.7 (199.9)	24.5 (122.3)
No, not at all	14.0 (174.4)	16.8 (125.4)	9.8 (48.9)

#### Findings by PCT and cause of death

Broadly, the relatives of patients who died of CVD were the least likely to report receiving enough support at the actual time of the death, regardless of PCT connection (Figure 9.46).

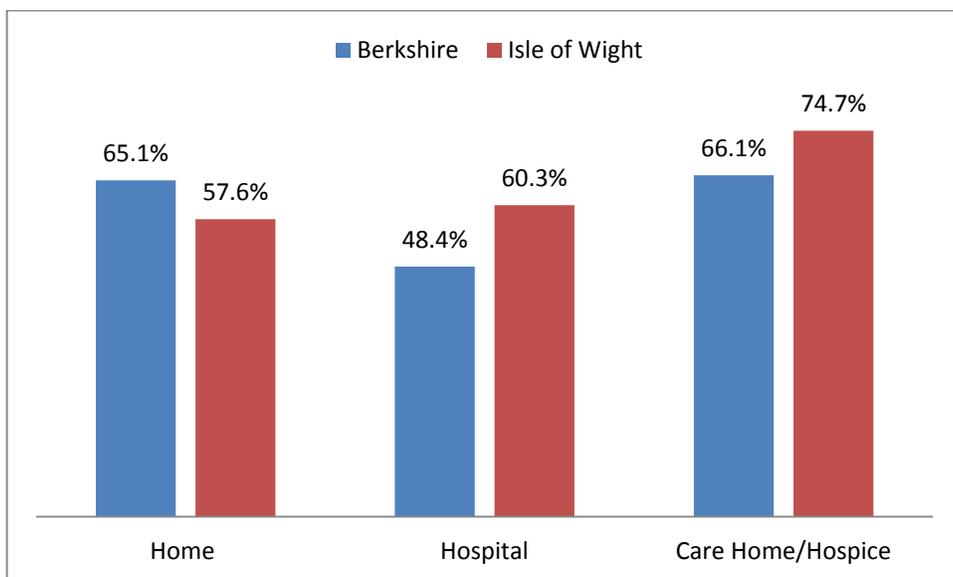
**Figure 9.44: Percentage reporting enough help and support at the actual time of the death, stratified by cause of death**



### **Findings by PCT and place of death**

Respondents whose relative died in a hospice or care home were the most likely to report having received sufficient support at the actual death (Figure 9.45).

**Figure 9.45: Percentage reporting enough help and support at the actual time of the death, stratified by place of death**



After s/he died, did staff deal with you or his/her family in a sensitive manner?

Yes

No

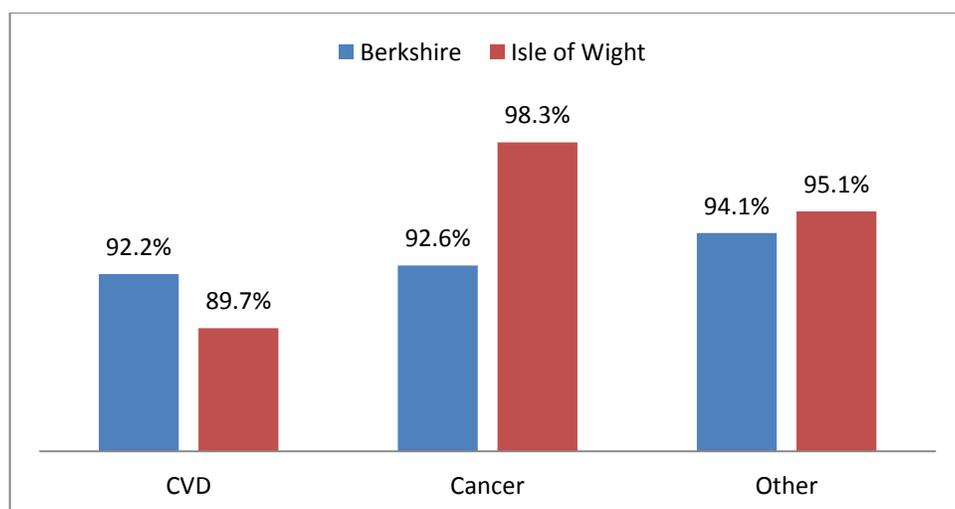
### Overall findings and by PCT

The majority of informants reported that they were dealt with in a sensitive manner by the staff across all care settings (93.4%). The PCTs received equal ratings for the way that staff dealt with relatives after the death (93.1% in Berkshire East and 93.9% in the Isle of Wight).

### Findings by PCT and cause of death

The differences between disease groups were small for this questionnaire item. The highest ratings were given to cancer patients in the Isle of Wight and lowest ratings to CVD patients in the Isle of Wight (Figure 9.46).

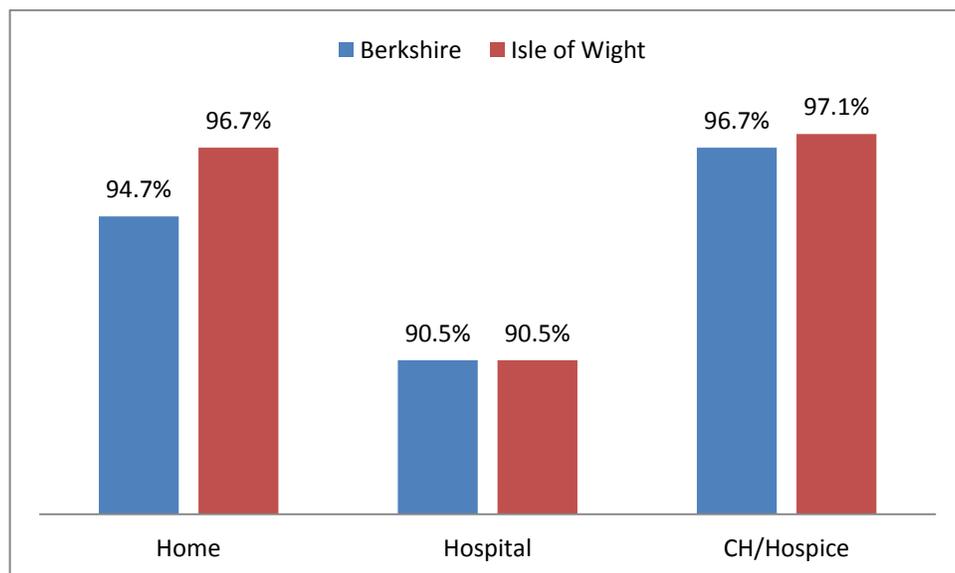
**Figure 9.46: Percentage reporting that staff dealt with the informant or family in a sensitive manner, stratified by cause of death**



### Findings by PCT and place of death

Hospital staff were less likely to deal with family in a sensitive way after the death than community staff (home deaths) or staff in care homes or hospices. Note that it is not possible to differentiate between care homes and hospices because of the way that deaths were assigned to strata (Figure 9.47).

**Figure 9.47: Percentage reporting that staff dealt with the informant or family in a sensitive manner, stratified by place of death**



### **Qualitative comments**

*“All I can say about the hospice care is they were the kindest people ever and I couldn’t have coped without them. [The patient] died in peace. Everyone around him was so kind and gentle. I have the chance to talk to bereavement counsellors when I’m ready. Thank you for all you do.”*  
(Berkshire East)

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

Yes

No

No, but I would have like to

No, but I did not want to anyway

### Overall findings and by PCT

Only a very small proportion of respondents had spoken to anyone from health or social services or a bereavement service after the death (Table 9.26). The proportion was slightly higher in the Isle of Wight than Berkshire East.

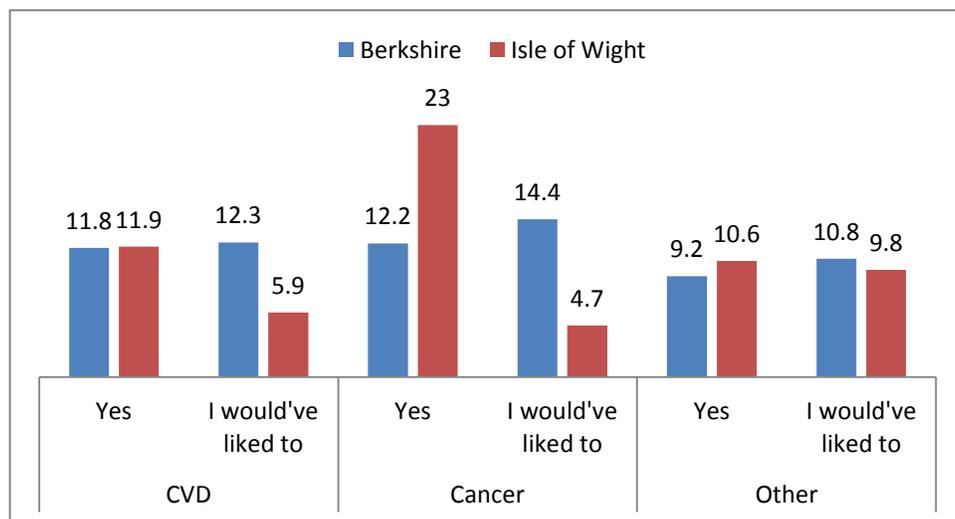
**Table 9.26: Bereavement support for carers (% with weighted frequencies in parentheses)**

	All sample	Berkshire East	Isle of Wight
<b>Yes</b>	12.3 (161.6)	10.9 (86.9)	14.5 (74.8)
<b>No</b>	54.9 (720.8)	55.4 (441.3)	54.1 (279.5)
<b>No, but I would have liked to</b>	10.4 (136.0)	12.4 (98.8)	7.2 (37.2)
<b>No, but I did not want to anyway</b>	22.4 (294.8)	21.3 (170.1)	24.2 (124.7)

### Findings by PCT and cause of death

Relatives of patients who died of cancer in the Isle of Wight were the most likely to have spoken with someone from a bereavement service. 14.4% of relatives of cancer decedents in Berkshire East would have liked to receive bereavement support compared to only 4.7% of relatives in the Isle of Wight (Figure 9.48). A similar trend was apparent for relatives of CVD decedents.

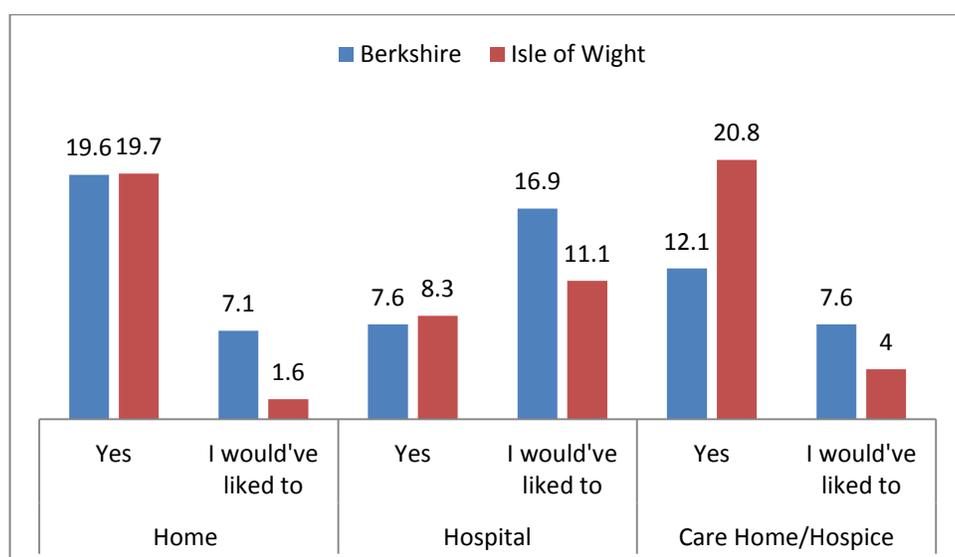
**Figure 9.48: Percentage of respondents who accessed or would like to have accessed a bereavement service, stratified by cause of death**



### Findings by PCT and place of death

Relatives of patients who died in a care home or hospice in the Isle of Wight were the most likely to receive bereavement support and a similar proportion of respondents whose relatives died at home were also in receipt of such support (Figure 9.49). Relatives of those who died in hospital were the most likely to report that they would have liked to receive bereavement support. Again, it should be noted that it is not possible to distinguish between bereavement support in hospices and care homes because of the way that deaths were assigned to strata.

**Figure 9.49: Percentage of respondents who accessed or would like to have accessed a bereavement service, stratified by place of death**



## 10. What is the required sample size for a VOICES survey?

In order to have statistical power to be able to make statistical comparisons between PCTs based on place of death and cause of death, a larger sample is required than if making comparisons based on PCT alone. However, to interpret the data appropriately and to be able to use the data to make recommendations for future practice, it may be necessary to analyse the effect of both place, and cause, of death.

In this survey, and despite the limits placed by financial resources, a census of the data collection sites was achieved. This was in part due to the exclusion of all Coroner-registered deaths: inclusion of those would have taken the eligible population from 1446 to 2185. However, for future VOICES surveys it is necessary to estimate the required sample size to make the comparisons of interest (PCT  $\times$  Cause of Death and PCT  $\times$  Place of Death).

The following net sample size calculations are based on a pre-determined desired margin of error (i.e. one half the total width of the 95% confidence interval), the size of the population and the proportion. Typically, the maximum variation occurs when the proportion is equal to 0.5 and hence this value is used in sample size calculations.

The net sample sizes are determined within sub-groups of interest (PCT  $\times$  Cause of Death and PCT  $\times$  Place of Death). The gross sample size is calculated by multiplying the net sample size by the inverse of the estimated response rate in the sub-group. If the estimated gross sample size is greater than the population size, a census should be carried out within the sub-group. The overall gross sample size is the total sample size aggregated across all sub-groups.

Since the aim of the national survey is to make comparisons across PCTs, the margin of error should be kept small. For example if the width of the interval for PCT  $\times$  Death by Cancer is 0.05 (margin of error 0.025) then proportions have to differ by at least 5% to be significantly different. The margin of error however needs to be balanced against the budget that is available to carry out the national survey.

Based on the pilot study, population sizes for sub-groups of interest (PCT  $\times$  Cause of Death and PCT  $\times$  Place of Death) are small. Moreover, given that the PCT may be replaced by GP Consortia, population sizes are likely to become smaller in the near future. We demonstrate a net sample size calculation based on the current pilot study where response rates were low (although 40% with the 'single posting' method). If the national survey is able to increase response rates, then gross sample size calculations can be reduced.

Table 10.1 and Table 10.2 present the net and gross sample size calculations for PCT × Cause of Death and PCT × Place of Death based on the population sizes from the ONS dataset and the achieved response rates from the pilot study. Varying margins of error are provided in the columns. The final total sample size should be the maximum of the two tables for the given margin of error. The formulae used to calculate these sample sizes can be found in Appendix J.

**Table 10.1: Net and Gross Sample size calculation of PCT × Cause of Death with finite population correction factor.** (Note that these calculations are based on proportions of 50% so rely on any question in the questionnaire)

PCT	Cause of Death		Population Size	Response Rate	Margin of Error			
					0.025	0.05	0.075	0.1
Berkshire East	CVD	Net	213	0.27	100	84	66	51
		Gross			213	213	213	187
	Cancer	Net	315	0.36	143	112	82	60
		Gross			315	315	312	229
	Other	Net	337	0.31	152	117	85	61
		Gross			337	337	278	201
Isle of Wight	CVD	Net	141	0.40	68	60	50	41
		Gross			141	141	126	103
	Cancer	Net	170	0.41	81	70	57	45
		Gross			170	170	141	112
	Other	Net	248	0.30	115	94	72	54
		Gross			248	248	242	182
Total Sample Size Required		Net	1424	0.33	659	537	413	313
		Gross			1424	1421	1230	952

**Table 10.2: Net Sample size calculation of PCT × Place of Death with finite population correction factor**

PCT	Place of Death		Population Size	Response Rate	Margin of Error			
					0.025	0.05	0.075	0.1
Berkshire East	Home	Net	123	0.39	59	53	46	38
		Gross			123	123	117	97
	Hospital	Net	461	0.27	201	144	98	68
		Gross			461	461	369	255
	Care Home/ Hospice	Net	281	0.37	129	103	77	57
		Gross			281	281	211	156
Isle of Wight	Home	Net	72	0.50	35	33	30	27
		Gross			72	71	66	53
	Hospital	Net	266	0.32	123	99	75	56
		Gross			266	266	235	175
	Care Home/ Hospice	Net	221	0.35	103	86	67	52
		Gross			221	221	191	146
Total Sample Size Required		Net	1424	0.33	651	519	394	297
		Gross			1424	1418	1183	883

Of course, if statistical comparisons within PCTs based on place and cause of death are not desired, the

overall sample size can be considerably smaller. For instance, assuming a margin of error of 0.025 and 80% power, a net sample size of 400 (gross sample size of 1000) would be required to detect a 15% difference between scores obtained for each PCT. Another way would be to assess the effect of place of death and cause of death independently from PCT. This would increase the sub-sample sizes and facilitate statistical comparison with smaller net sample sizes.

It is possible to further increase the size of the target population by conducting recruitment at two time points. Due to time constraints, this survey conducted one extraction from the death certificates database and recruited deaths over a six month period (6–12 months after the death). Therefore, some of the sample were contacted 6 months after the death of their relative, whilst others almost a year after the death (approaching relatives 12 months post-death was avoided because of the distress associated with death anniversaries). This meant that deaths that occurred over a six month period were included, rather than a full 12 month period. Thus, it would be possible to conduct one extraction from the database but send out survey invitations on two occasions (spaced by six months), thereby doubling the size of the target population. This would also increase the representativeness of the sample by accounting for seasonal variation in deaths.

Assuming a response rate of 35% and confidence intervals of 95%, a minimum sample size of 700 is required **for each PCT/GP Consortium** in order to make between PCT/GP Consortium comparisons based on place of death and cause of death.

## **11. Recommendations for future VOICES surveys**

The following recommendations are intended to provide guidance on the planning and conduct of future national end of life surveys.

### **11.1. Questionnaire**

The VOICES questionnaire is designed as a validated, sensitive measure of experiences at the end of life from the perspective of bereaved relatives and is recommended as the data collection tool of choice in a survey of end of life care.

### **11.2. Sample and eligibility criteria**

In deciding upon the size and composition of the sample and drawing up inclusion/exclusion criteria there are some essential requirements. In particular, it will be important:

- a. to ensure representativeness and to capture all deaths, including those where no formal care was received. To achieve this, the sample should be identified through death certificates which requires collaboration with ONS.
- b. to facilitate comparisons between care providers by cluster sampling according to PCT/GP consortium.
- c. to utilise stratified sampling to ensure proportional representation of deaths, thus facilitating comparisons – both between care providers and the place/cause of death (whether these comparisons can be made within PCTs, or in the whole sample, depends upon the sample sizes of each cluster – PCT/GP Consortium).
- d. to ensure the sample size is sufficiently large to make the comparisons of interest. Sample sizes under 700 in each PCT are unlikely to provide adequate statistical power to perform analyses based on place/cause of death between PCTs. It may therefore be necessary to combine GP Consortia if population sizes are too small.
- e. to exclude all deaths coded with ICD-10 codes ranging from S000–Z99, thus only excluding suspicious deaths, suicides and accidents (ONS are happy to take this approach).
- f. to exclude deaths in those aged under 18 years.
- g. to exclude deaths registered as occurring ‘elsewhere’

In deciding upon the time frame to be used in the sample, a number of alternatives might be considered. The window of dates could be extended from 6–12 months to 5–12 months in order to increase the size of the target population. Alternatively, the extraction of deaths from the ONS database could include deaths over a whole year, rather than a six month period. Recruitment might then be conducted in two phases, at six month intervals, thus increasing the size of the target population and accounting for the natural seasonal fluctuation in deaths. However, whichever

recruitment method is used, caution should be exercised to ensure that invitations and reminders are not sent out at the anniversary of the death.

After data collection and input, weights can be applied to correct non-response bias.

### **11.3. Recruitment methods**

It is recommended that the single posting method be adopted as the optimal recruitment method. It is associated with the highest response rate and does not produce a greater number of complaints than the 'opt in' method.

### **11.4. Survey management**

NHS ethical approval may not be judged necessary if a VOICES survey does not use NHS premises, staff or patients, as was the case in this survey.

The following pointers are intended as a guide and represent good practice:

- a. Unique IDs that describe PCT/GP consortium, sex, and other strata assist in reducing error in survey management
- b. Use of an 'opt out' slip is a reliable method of ensuring that those not wanting to take part do not get reminders.
- c. Online methods can be used to supplement the paper version of the questionnaire. This may help to increase response. An online version of the questionnaire can be hosted through a VOICES survey website
- d. Given that ethnicity is not detailed on death certificates, linkage with ONS ethnicity datasets can be employed to ascertain the approximate proportion of the sample who belong to BME groups
- e. In order to ensure that sudden deaths are better represented in the sample, study documentation could further emphasise that the questionnaire is designed to understand the health and social care experiences of people who died from any condition, even after a sudden death.
- f. Two reminders letters are necessary to increase response but the timing of these reminders is important given that participants take a considerable time to complete/decide to complete the questionnaire. Reminders scheduled at three week intervals seem optimal
- g. To increase accessibility of the questionnaire, large print and braille versions of the questionnaire can be made available alongside a large print introductory statement on the invitation letter
- h. Establishing a telephone helpline facility would provide support in questionnaire completion and enable participants to ask questions about the nature or purpose of the survey

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

- a. Two centralised telephone complaint lines should be established: one for complaints about the research and the other for complaints about care. The latter should align with the recently published New Health System Architecture for Complaints and could be used to direct respondents to PALS
- b. Survey participants should have ready access to emotional support from an appropriate organisation in the event that completing a questionnaire provokes distress. This might be best provided by an organisation such as Cruse which is experienced in responding to distress in the bereaved. Ideally they would be able to meet the respondent face to face, if judged necessary.
- c. Given that emotional support should be available for all respondents, the provision of a multilingual support service (with interpreters representing the predominant languages in the data collection sites) is desirable.

### **11.6. Engaging BME groups**

- a. A Language Support Document should be enclosed with the initial invitation letter to direct potential respondents to an interpreting service
- b. If the DH wishes to capture experience/quality from the perspective of this group, the VOICES survey is not likely to be a particularly productive way of achieving this. Instead, another method of data collection, such as focus groups, should be employed at the local level.

### **11.7. Promotional activities**

- a. Promotion at the national level is likely to be beneficial, and local level promotion (carried out by individual Trusts) might also be helpful in further increasing response
- b. A survey website would act as a useful source of information about the survey and could be used to outline planned analyses and potential impact as well as information about the VOICES questionnaire. Promotional material could direct interested parties to this website
- c. A press release could be issued by the Department of Health to national press organisations. Individual Trusts could also choose to issue press releases (based on a template issued to them) to local press organisations to further increase response in their area
- d. Health and social care staff should be made aware of the survey in the event that they are asked to provide further information.
- e. Consideration should be given to the use of 'prior warnings' about the survey or 'VOICES information leaflets' which could be issued to informants upon death registration.

## References

1. Department of Health (2008) End of Life Care Strategy – promoting high quality care for all adults at the end of life. London: HMSO
2. Department of Health (2010) NHS Outcomes Framework. London: HMSO
3. Fakhoury W.K.H, McCarthy M, Addington–Hall J.M. Which informal carers are most satisfied with services for dying patients? *European Journal of Public Health*, 1996; 6: 181–187
4. McPherson C.J, Addington–Hall J.M. How do proxies' perceptions of patients' pain, anxiety, and depression change during the bereavement period? *Journal of Palliative Medicine*, 2002; 12–19
5. McPherson C.J, Addington–Hall J.M. Judging the quality of care at the end of life: can proxies provide reliable information? *Social Science and Medicine*, 2003: 95–109
6. Addington–Hall J.M, McPherson C.J. After–death interviews with surrogates/bereaved family members: Some issues of validity. *Journal of Pain and Symptom Management*, 2001;22: 784–790
7. Addington–Hall J.M, McCarthy M. Regional Study of Care for the Dying: methods and sample characteristics. *Palliative Medicine*, 1995; 9: 27–35
8. Addington–Hall J.M, Walker L, Jones, C, Karlson S, McCarthy M. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. *Journal of Epidemiology and Community Health*, 1998; 52: 802–807
9. Siemiatycki J. A comparison of mail, telephone and home interview strategies for household health surveys. *American Journal of Public Health*, 1979; 69: 238–254
10. Aspinall F, Hughes R, Dunckley M, Addington–Hall J.M. What is important to measure in the last months and weeks of life? A modified nominal group study. *International Journal of Nursing Studies*, 2006: 393–403
11. Hughes R, Saleem T, Addington–Hall J.M. Towards a culturally acceptable end of life survey questionnaire: a Bengali translation of VOICES. *International Journal of Palliative Care Nursing*, 2005; 11: 116–123
12. Burt J, Shipman C, Richardson A, Ream E, Addington–Hall, J. The experiences of older adults in the community in the last three months of life: a national survey of bereaved relatives. *Age and Ageing*, 2010; 39 (1): 86–91
13. Addington–Hall J, O'Callaghan A. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in–patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine*, 2009; 23: 190–197
14. Young A, Rogers A, Addington–Hall J. The quality and adequacy of care received at home in the last three months of life by people who died following a stroke: a retrospective survey of

- surviving family and friends using the 'View of Informal Carers – Evaluation of Services' questionnaire. *Health and Social Care in the Community*, 2008; 16: 419–428
15. Elkington H, White P, Addington–Hall J, Higgs R, Edmonds P. The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine*, 2005; 19: 485–491
  16. Rogers A, Karlsen S, Addington–hall J. Dying for care: the experiences of terminally ill cancer patients in an inner–city health district. *Palliative Medicine*, 2000; 14: 53–54
  17. Ingleton C, Morgan J, Hughes P, Noble B, Evans A, Clark D. Carer satisfaction with end of life care in Powys, Wales: a cross–sectional survey. *Health and Social Care in the Community*, 2004; 12: 43–52
  18. Fielding N, Less R.M, Blank G. (2008) *The Sage Handbook of Online Research Methods*. London: Sage