



First national VOICES survey of bereaved people: key findings report

'How people die remains in the memory of those who live on'

Dame Cicely Saunders

Founder of the Modern Hospice Movement

July 2012

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First published July 2012

Published to DH website, in electronic PDF format only.

www.dh.gov.uk/publications

DH INFORMATION READER BOX

Policy	Clinical Commissioner Development Provider Development Improvement and Efficiency	Estates IM & T Finance Social Care / Partnership Working
HR / Workforce Management Planning / Performance		
Document Purpose	For Information	
Gateway Reference	17865	
Title	First national VOICES survey of bereaved people	
Author	DH / NHS Medical Directorate / End of Life Care	
Publication Date	03 July 2012	
Target Audience	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Allied Health Professionals, GPs, Voluntary sector organisations	
Circulation List		
Description	This report summarises the main findings from the first national VOICES survey of the bereaved. The survey was run by the Office for National Statistics (ONS), on behalf of the DH, and the full data are available on the ONS website.	
Cross Ref	End of Life Care Strategy (2008)	
Superseded Docs	N/A	
Action Required	N/A	
Timing	N/A	
Contact Details	End of Life Care Team Department of Health Room 402, Wellington House 133-155 Waterloo Road London SE1 8UG 020 797 24967 www.dh.gov.uk	
For Recipient's Use		

First national VOICES survey of bereaved people: key findings report

This report highlights the key findings from the first national VOICES survey of bereaved people, which was undertaken by the Office for National Statistics (ONS) on behalf of the Department of Health. The report was developed with support from the ONS, and complements the survey data the ONS published on 3 July.

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Introduction

- 1.1 This report provides an overview of the findings from the first ever national survey of bereaved relatives in England. The overall aims of the survey were to assess the quality of care delivered to people in the last three months of their lives in this country and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients.
- 1.2 The survey was commissioned by the Department of Health in line with a commitment made in the End of Life Care Strategy (2008)¹ to carry out surveys of bereaved relatives. Until now very little systematic information has been available about the quality of care delivered to people approaching the end of life, though reports from the Healthcare Commission and others have highlighted deficiencies in care.
- 1.3 The approach adopted for this survey was to send a questionnaire by post to the person who had informed the registrar of deaths about the death; this was usually a relative or friend of the deceased. The informant was asked to pass the questionnaire on to another family member or friend of the deceased if appropriate. The questionnaires were sent out between four and eleven months after the patient had died.
- 1.4 This approach is based on extensive research by Professor Julia Addington-Hall and colleagues², asking bereaved relatives about their perceptions of the care given to recently deceased persons. The Views of Informal Carers for the Evaluation of Services (VOICES) approach has been successfully used to assess the quality of care given to patients dying from a range of conditions (e.g. cancer, stroke and chronic obstructive pulmonary disease) and in different locations⁽³⁻⁷⁾. This approach is now well established and has been shown to be valid in relation to evaluation of services⁽⁸⁻¹²⁾.
- 1.5 Following publication of the End of Life Care Strategy, Professor Addington-Hall was commissioned by the Department of Health to modify the VOICES questionnaire in order to measure key aspects of the quality of care identified in the strategy. The resulting short form of the VOICES questionnaire (VOICES-SF) was subsequently piloted in two Primary Care Trusts¹³ (East Berkshire and the Isle of Wight) in 2010/11. These pilots demonstrated the feasibility of the approach and the acceptability of the new survey tool. The findings from the pilots also showed that the survey could detect differences in the quality of care provided in different settings (e.g. hospitals versus hospices). Minor modifications were made to the survey tool following the pilots. In particular an item regarding overall quality of care in the last three months of life was added.

Methods

- 2.1 The national survey was conducted by the Office for National Statistics (ONS) on behalf of the Department of Health. The study was designed to enable

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comparisons to be made between the quality of care given to people dying at different ages (e.g. less than 65 years, 65-79 years or 80 years or more) and different causes of death (cardiovascular, cancer or other) and for people receiving care in different settings in the last three months of life (e.g. home, hospital, care home and/or hospice). Importantly the sample size was chosen in order to enable comparisons to be made in the delivery of care between the 51 Primary Care Trust (PCT) clusters in England in 2010/11. On average these clusters have populations of around more than 800,000 adults (range 383,000 to 2,080,000), of whom between 3,300 and 23,700 adults die in a year.

- 2.2 The sample of informants of death to whom the questionnaire survey was sent was drawn from the 306,409 deaths among adults which occurred between 1st November 2010 and 30th June 2011. A total of 16,264 (5.3%) people who had died were excluded because the death was due to accident, suicide or homicide (7,228), had occurred 'elsewhere' than the designated locations (3,491) or because address details of the informant were missing (5,545). All of the latter group were deaths which had been referred to a coroner. Of the remaining 290,145 with informant details around one third (35.2%) were deaths which had been referred to a coroner and two thirds (64.8%) were not.
- 2.3 From the 290,145 eligible for the survey a sample of 1 in 6 (around 49,000) was drawn for the actual survey. Sampling methods were implemented to ensure the sample represented deaths in England by sex of the deceased, cause of death, place of death, age and region.
- 2.4 As is standard in most surveys there were three mail outs to informants. The first comprised the mail-merged personalised questionnaire, a prepaid return envelope, an information leaflet and a reply slip [see web appendix B]. A reminder letter was sent three weeks after the mail-out to non-responders. A final invitation to take part was sent after the reminder letter together with a further questionnaire, envelope, leaflet and reply slip. An online version of the questionnaire was also provided, with information about this given in the letter.
- 2.5 It was recognised that the survey contained questions of a sensitive nature and was addressed to people who had been bereaved within the previous year. A free national telephone number was provided for the ONS Survey Enquiry Line, which is open for extended hours Monday to Friday and on Saturday mornings. The survey team worked closely with Cruse Bereavement Care, with information being provided in the letter and information leaflet and from the Survey Enquiry Line team.
- 2.6 The version of the VOICES-SF questionnaire used in the survey has 59 questions [70 items]. These cover:
 - details about the respondent (e.g. age, sex and relationship to the deceased)

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- details about the deceased (e.g. duration of final illness and settings where the deceased had received care in the last three months of life and ethnicity and religion of the deceased)
- perceptions of the quality of care delivered in each care setting including overall quality of care and dignity and respect given to the deceased person by staff
- coordination of care within the community and between hospitals and community services
- quality of care given in the last two days of life
- decision making toward the end of life
- awareness of likely death and preferences and choice about where to die
- respondents' views on ultimate place of death
- support provided to family/friends in the last three months of the person's life and after the death.

2.7 The information provided by the respondents was combined with information known to ONS from the death certification process. This included age, gender, place of death, cause of death and country of birth of the deceased, together with their postcode which was used to assess level of deprivation.

2.8 For clarity in this short report almost all percentages in the Tables are rounded to the nearest whole number. Full details with confidence intervals are available in the set of tables published on the Office for National Statistics website (www.ons.gov.uk).

Results

3.1 The VOICES-SF questionnaire was sent out in November 2011 to 48,766 adults who had registered a death 4 to 11 months earlier. A total of 22,292 people responded giving a response rate of 45.7%. No response was received from 29.7%; 21.7% sent the reply slip choosing to opt out and 2.9% did not reach the respondent and were returned to sender.

3.2 A full comparison of responders and non responders is shown in the web appendix. Response rates were significantly higher ($p < 0.001$) when the deceased was female, aged 80 or over, died in a care home or hospice, died from cancer, was in the least deprived quintile and was born in the UK.

3.3 The characteristics of the patients for whom a response was received are shown in Table 1. Over 60% of the patients were aged 80 years or more at the time of death with nearly a quarter (23%) being aged 90 or more. Around one

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half (51%) died in hospital, with 21% dying at home, 22% in a care home and 6% in a hospice. Around 93% had been born in the UK.

- 3.4 Around 90% of respondents were able to provide information on duration of illness. Among those with known duration of illness over 40% had the illness for a year or more and a further 13% for 6-12 months. In contrast, around 10% had a sudden death or died within 24 hours and around 15% were ill for between 1 day and 1 month (Table 1b).
- 3.5 Respondents were generally much more able to answer questions about services delivered at home than in other settings. There were high levels of nil responses or 'don't knows' for use of district/community services or out of hours services. These questions were only asked where the patient had been at home for some or all of the last three months of life and where the death had not been sudden. Despite this the most highly used services reported were GP services (73%), hospital services (63%) and district/community nurses (50%) – Table 2.

Overall quality of care in the last three months of life

- 4.1 Overall quality of care across all services and settings was reported for around 84% of patients. Of these 12% rated the care given as outstanding, 30% as excellent, 33% reported care as good, 14% as fair and 10% as poor – Table 3. The highest proportions of ratings as outstanding were for patients who died in hospices (20%) and at home (19%) compared with 7% for hospitals, those who died of cancer (16% versus 9% for CVD and 11% other) and patients under 65 years (16% vs. 11% for those aged 80 or over).
- 4.2 Ratings of quality of care by care setting are shown in Table 4. Care was rated as excellent for 78% who had been in a hospice and as excellent or good by 92%. The combined 'excellent' and 'good' percentages for other care settings and services were as follows: Care homes 81%; district/community nurses 82%, hospital doctors 74%, GPs 72%, hospital nurses 68% and out of hours services 65%.
- 4.3 Being shown dignity and respect by staff was highest in hospices (87% "all of the time" for hospice doctors and 80% for hospice nurses); followed by district/community nurses (79%); GPs (72%); care home staff (61%); hospital doctors (57%) and hospital nurses (48%) – Table 5. Dignity and respect ratings were generally highest for patients with cancer as the cause of death, though no significant difference by cause of death was observed among hospital doctors – Table 6. In care homes, dignity and respect ratings were highest for patients aged under 65 years compared with the older age groups. In the hospital setting, patients who died at 80 years or older were rated lowest compared with both the under 65 and 65 to 79 year age groups – Table 7.

Coordination of care

- 5.1 Only around 40% of respondents completed the question asking whether community services worked well together as this question was only asked where the patient had been at home for some or all of the last three months of life and where the death had not been sudden. In addition some reported no community care had been received. Among those who responded to this item, 45% reported 'yes – definitely' and a further 42% 'yes – to some extent'. Community services working well together was highest for patients who died at home (58% yes definitely), cancer patients (50%) and for younger patients (for those under 80 years) – Table 8.
- 5.2 Around 40% responded to the question asking whether hospital services worked well together with GP and other services outside hospital – Table 9. The ratings were lower than for the previous item, with only 33% responding 'yes-definitely'. Significantly higher ratings were reported for cancer patients (36%) and for those who died at home (39%). No difference was observed according to the age of the patient at death.

Relief of pain and of suffering in the last three months of life

- 6.1 Pain relief was reported as being provided 'completely, all of the time' most frequently among those in hospices (62%) and least frequently among those at home (17%) – Table 10a. In hospices and at home relief of pain was reported to be highest for those who died of cancer. In hospitals and care homes relief of pain was similar across cancer, CVD and other causes – Table 10b.

Care and support in the last two days of life

- 7.1 The overwhelming majority of patients were in a single location for the last two days of life (Table 11a), with hospital (44%) being the most common location. Cancer patients were more likely to be at home or in a hospital and least likely to be in a care home. One-fifth were in a hospice in the last 2 days of life (Table 11b). The oldest age group (80+) were much more likely to be in a care home and least likely to be at home in the last 2 days of life (Table 11c).
- 7.2 Ratings for dignity and respect shown by different staff groups were higher for the last two days of life (Table 12) than for the last 3 months of life (Table 5). Ratings for doctors and nurses were broadly similar and for both doctors and nurses the highest ratings were where the patient died in a hospice. Ratings were similar for care from doctors and nurses where the patient died at home or in a care home. Ratings for hospital staff were lowest (Table 12).
- 7.3 The large majority of patients were reported to have had their personal needs met in the last two days of life (79% strongly agree or agree); to have had their nursing needs met (79%) and to have had adequate privacy (82%) However, a significant minority (5%) of respondents strongly disagreed on each of these

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items (Table 13a). Ratings were lowest on all three areas of help received for those patients who died in hospital (71% personal needs, 71% nursing needs and 72% adequate privacy) and highest for those who died in a hospice (96%, 95% and 95% respectively) – Table 13b.

- 7.4 The large majority of respondents reported that support received in the last 2 days of life was excellent or good in relation to relief of pain (79%), relief of other symptoms (74%) and support to stay where they wanted to (80%). Ratings for emotional support (71%) and spiritual support (67%) were somewhat lower. These aspects of support also had the highest percentages of ‘poor’ support – Table 14.

Decision making, communication, preferences and choice at the end of life

- 8.1 Around two thirds of respondents reported that no decisions had been made about care which the patient would not have wanted (Table 15). However 17% said yes to this question, with 19% reporting ‘don’t know’. The percentage reporting ‘yes’ was lowest for patients who died at home and those aged less than 80 years. There was little difference across cause of death.
- 8.2 The large majority of patients (85%) were involved in decisions about their care as much as they wanted, with very few reporting that they would have preferred less involvement. Involvement was highest for those who died at home (92%) and for those who died of cancer (88%). There were no significant differences by age at death (Table 16).
- 8.3 Overall, a minority of patients knew they were going to die (32%). The proportion of patients who were reported as definitely knowing they were likely to die was much higher for cancer patients (Table 17). Only around one quarter of respondents responded to the question about whether patients were told they were likely to die in a sensitive way. Among those who did respond to this item nearly 3 in 5 (59%) reported ‘yes, definitely’; but 12% reported ‘no, not at all’. Older people (over 80 years) were most likely to have been told in a sensitive way. There were no significant differences between those who died in their own home, a care home or in a hospice. (Table 18).
- 8.4 Almost 90% of respondents answered the question ‘had the patient expressed a preference of where they wanted to die?’ (Table 19). Overall, less than half of all patients were reported to have expressed a preference for where they would like to die (44%). The proportion was highest for cancer patients and those who died at home. The proportion was reported to be lowest among people aged 80 or over. For those who had expressed a preference the majority (71%) preferred to die at home.
- 8.5 Around 58% of respondents answered the question “did the patient have enough choice about where they might die?” A nil response was given by 16%

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and 26% said the patient died suddenly (Table 20). Of those who did respond over half (51%) said that the patient did have enough choice about where they might die, but nearly a quarter (23%) did not. The remainder (26%) were unsure (Table 20). Patients dying from cancer, those who died at home or in a hospice and those who were younger (<80 years) at death were more likely to be reported as having had enough choice of where they might die.

- 8.6 The large majority of respondents (82%) thought that the patient had died in the right place (Table 21). Cancer patients, those who died at home or in a hospice and those aged 80 years or more were more likely to be reported to have died in the right place by respondents.

Support for relatives, friends or carers at the end of life

- 9.1 This section of the survey focused on the relatives, friends or carers themselves as opposed to obtaining their views on the care delivered to the deceased. Only half of respondents answered the global question about support for carers in the last three months of life. This question was only asked where the patient had been at home for some or all of the last three months of life and where the death had not been sudden. A nil response was given by 41% and 9% said that help was not needed.
- 9.2 Half of those who responded to this item said that they had received as much support as they wanted and 20% did receive support but wanted more. In contrast 15% did not get enough support despite trying and 15% would have liked support but didn't ask (Table 22). Relatives of cancer patients and those who died at home or in a hospice were more likely to get as much support as they wanted.
- 9.3 Around 60% of respondents answered the question about whether they were able to discuss worries and fears with their GP. A nil response was given by 30% and 7% reported that they had no worries or fears to discuss (Table 23). Of those who answered the question, 56% reported that they were able to discuss worries and fears as much as they wanted. A further 17% were able to discuss worries or fears but wanted more and 8% tried to discuss fears or worries but were not able to. Relatives of cancer patients and those who died at home were most likely to be able to discuss fears and worries as much as they wanted with their GP. Younger respondents (age <60 years) were less likely to report being able to discuss worries and fears as much as they wanted (49% compared with 63% in those aged 60 years and over).
- 9.4 Over 80% of respondents answered the question asking whether they were involved as much as they wanted in decisions about the patients' care. Of these the large majority (78%) reported that they were involved as much as they wanted. Only a very small number (0.3%) would have preferred less involvement (Table 24). Relatives of patients who died in hospital were least likely to report being involved as much as they wanted in decisions. There was

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no significant difference by cause of death. Younger respondents (under 60 years) were more likely to report that they would have wanted more involvement (27% compared with 18% in those aged 60 years and over).

- 9.5 More than 80% of respondents answered the question asking whether support for the respondent/family was adequate at the time of the death (Table 25). Over half (59%) said they and/or their family definitely had received adequate support, but in contrast 14% reported that they had not at all. Relatives of patients who had died in a hospice were most likely to report adequate support (85%). Younger respondents (under 60 years) were less likely to report having received adequate support (54% compared with 63% in those aged 60 years and over).
- 9.6 Around 80% of respondents answered the question “after the patient died did the staff deal with you or the family in a sensitive manner?” More than 9 out of 10 (93%) reported being dealt with sensitively after the death. The proportion was particularly high among respondents of those who died in a hospice (99%), but was over 90% in each care setting and for all causes of death (Table 26).
- 9.7 Around two thirds of respondents did not want to talk to anyone from health or other services after the death (Table 27). Respondents of those who died in a hospice were the most likely to have talked to someone after the death. Younger respondents and female respondents were more likely to have wanted to talk to someone after the death.

Variations by PCT cluster

- 10.1 Variations in responses to 11 key items by PCT cluster are shown in Table 28 and in the summary table (Table 29). On each item substantial variations are evident between the PCT cluster with the highest and lowest score. In relation to overall quality of care in the last three months of life a difference of nearly 20% was observed between the highest and lowest PCT cluster (51% to 32%). Similar magnitudes of difference between highest and lowest were observed for coordination of care, dignity and respect and relief of pain in the last 2 days of life. Somewhat smaller differences were observed for coordination of care, dignity and respect and relief of pain in the last 2 days of life. Somewhat smaller differences were observed in relation to the questions about preferences, choice, decision making and choice. Larger differences between highest and lowest were observed in relation to the items about support for carers.
- 10.2 Further details on these key 11 questions can be found in web Appendix A. Full details of all the comparisons for all PCT Clusters will be published as a separate report in the autumn.

Quality of care for people with dementia

- 11.1 Around one–fifth of patients had dementia or senility mentioned on their death certificate. This varied across the cause of deaths groups: 15% of cardiovascular deaths, 4% of cancer deaths and 37% of ‘other’ deaths had dementia mentioned. More than half of deaths in care homes had dementia mentioned (56%), as did 13% of hospital deaths, 10% of deaths at home and 1% of hospice deaths. Almost a third of patients aged 80 years or over had dementia mentioned (32%), 7% of those aged 65-79 and 1% of those aged under 65 years.
- 11.2 Respondents of patients where dementia was mentioned were more likely to rate the overall quality of care as outstanding or excellent (46%) compared with those without (42%), and were less likely to rate the overall quality of care as poor (7% versus 10%) – Table 30a.
- 11.3 Respondents of patients where dementia was mentioned were more likely to rate the quality of care from GPs as good compared with those without, and were less likely to rate the quality of GP care as poor. A similar picture was found for care homes. Respondents of patients where dementia was mentioned were more likely to rate the quality of care as excellent compared with those without, and were less likely to rate the quality of care as poor (Table 30b). While respondents of patients where dementia was mentioned were less likely to rate the quality of care from hospital staff as excellent compared with those without, they were also more likely to rate the care as good.
- 11.4 There was little difference across the patient groups for the dignity and respect shown by GPs. Respondents were more likely to rate that dignity and respect was shown all the time by care home staff to patients with dementia compared with those without. Respondents were less likely to rate that dignity and respect was shown all the time to patients with dementia compared with those without by hospital staff (Table 30c).

Discussion

- 12.1 This is the first ever large scale survey which has assessed the quality of support and care given to people approaching the end of life in England and to their relatives/friends. The feasibility of the approach has been demonstrated. The support of the ONS Survey Enquiry Line team was important and they reported receiving fewer calls than for other surveys of this size. A small minority of calls of a particularly sensitive nature or expressing a serious complaint were sent through to the Survey Manager who dealt with them personally. Contact details for the national charitable organisation Cruse Bereavement Care were included in leaflets, letters and in the questionnaire to respondents, and passed on by the Survey Enquiry Line team where appropriate.

- 12.2 The use of bereaved relatives as a proxy for the views of people approaching the end of life has been extensively tested in research settings. The validity of this approach has been well established especially for questions on service provision and use and evaluation of care, though less robust for subjective symptoms such as pain¹². The response rate of 45.7% is comparable with that obtained in previous surveys of bereaved relatives and was higher than that observed in the two pilot PCTs (40.0%) which used the same questionnaire and 'three mailing' method. It was also higher than the GP Patient Survey: Year 2011/2012 which obtained a response rate of 38%.
- 12.3 As expected, there was some response bias with higher response rates relating to patients in the least deprived quintile and who were born in the UK. However, the size of the survey means that meaningful comparisons could be made between groups. The survey size also allowed for meaningful comparisons at the PCT cluster level.
- 12.4 Information on duration of illness prior to death is not available from routinely collected datasets. The findings suggested that around 10% die suddenly or within 24 hours. This excludes the relatively small number who died from accidents, suicide or homicide that were excluded from this study, but who constituted about 2.4% of all deaths in the study period. In contrast over half of the patients had been ill for 6 months or more prior to death.
- 12.5 Reported figures on sudden death vary quite widely. In the current study in answer to the question about duration of illness 8% responded "sudden death", whereas in answer to the question about enough choice where they might die, 26% responded "died suddenly". An explanation for this is likely to be that for a considerable proportion of patients with known illnesses their ultimate death is perceived as sudden and/or unexpected by relatives. Of those where the respondent answered "died suddenly", this was higher where the patient died of cardiovascular disease compared to cancer (40% versus 12%) and higher for hospital deaths than hospice deaths (33% versus 6%).
- 12.6 The overall quality of care across all settings was higher for cancer deaths, for deaths occurring in hospices and for younger deaths (under 65 years) although these three groups strongly overlap. The ratings of outstanding and excellent were lowest for patients who died in hospital. This pattern was confirmed by the quality of care questions which related specifically to each care setting, irrespective of where the patient died. Hospital doctors and nurses continued to be rated lowest for excellent quality of care and hospices were rated highest.
- 12.7 This survey has highlighted significant differences in quality of care according to the age of the patient at death, cause of death and place of death. It is, of course, important to note that age at death, cause of death and place of death are interrelated. For example, 92% of hospice deaths are due to cancer and 83% of care home deaths were in those aged 80 years or older at death. Two-thirds of cardiovascular deaths and deaths due to other causes were in the 80

years and older group while two-thirds of cancer deaths are in the under 80 year age group. In the future, with aggregated years of data, combined groups of cause and place of death can be compared.

- 12.8 On most items younger people (<65 years), those dying from cancer and those dying at home or in a hospice were reported to have received better care. In contrast on most items those who died in hospital were reported to have received the poorest care. An interesting exception to this pattern was that patients aged 80 or over were reported to have been told they were likely to die in a sensitive manner. A further exception related to relief of pain, where those who died at home fared worst.
- 12.9 Most respondents reported that no decisions had been made that the patient would not have wanted and (if they were able to answer the question) that the patient had been told they were likely to die in a sensitive way. However, on both of these items a significant minority reported the opposite.
- 12.10 In relation to preferred place of death, less than half were reported to have expressed a preference for where they would like to die. Although half of those answering this question felt that the patient had enough choice, a quarter did not. Despite this, the large majority of respondents felt that the patient had died in the right place.
- 12.11 Support for family and carers themselves was variable, particularly during the patients' illness where around half of those responded that they didn't get any support or would have wanted more. While a high proportion (over 90%) reported being dealt with sensitively after the death, around 20% reported they would have liked more support following the death and 25% wanted more support from the GP.
- 12.12 This survey has highlighted wide variations in quality of care between the 51 PCT clusters in operation at the time of the survey. On the key items relating both to quality of care in the last three months of life and the last two days of life a difference of around 20% was observed between the highest and lowest cluster. Differences in relation to support for carers were of a similar magnitude. This indicates that there is very considerable scope for improving service quality by bringing areas of the country which are performing least well up to the levels already being achieved elsewhere.
- 12.13 The quality of care for patients where dementia was mentioned on the death certificate was generally rated of a similar standard to those without. For GPs and care homes, positive ratings of care were somewhat higher for patients with dementia than without but the opposite was true for hospital doctors and nurses. Three-quarters of responses reported GPs treated their patients with dignity and respect all of the time and this did not differ between patients with or without dementia. For care homes, such ratings were slightly higher for patients with

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dementia than without. Again, respondents were less likely to rate that dignity and respect were shown all the time by hospital staff.

12.14 In conclusion, this survey has demonstrated that some patients receive high quality care, irrespective of age, cause of death or care setting. However, it has also revealed wide differences between patient groups and between care settings. This survey can be used as a baseline against which to measure progress on improving end of life care both at the national and local levels.

Tables

Table 1a: Characteristics of patients for whom a response was received

		Numbers	Percentage
	Total	22,292	100
Age	18-59	1,506	7
	60-69	2,456	11
	70-79	4,594	21
	80-89	8,622	39
	90+	5,114	23
Gender	Male	10,114	45
	Female	12,178	55
Place of death	Home	4,698	21
	Hospital	11,267	51
	Care home	4,916	22
	Hospice	1,411	6
Cause of death	CVD	6,655	30
	Cancer	6,970	31
	Other	8,667	39
Deprivation	1. Most deprived	3,716	17
	2.	4,228	19
	3.	4,827	22
	4.	4,823	22
	5. Least deprived	4,698	21
Country of birth	UK	20,702	93
	Elsewhere	1,590	7

Table 1b: Characteristics of patients for whom a response was received (continued)

Reported duration of illness	%	% of known
Sudden death	7	8
Less than 24 hours	2	2
1 day to 1 week	4	5
1 week to 1 month	9	10
1-6 months	18	19
6-12 months	11	13
1 year or more	39	44
Duration not reported	10	-

Figures may not add due to rounding

Among those with known duration of illness over 40% had the illness for a year or more and a further 13% for 6-12 months. In contrast, around 10% had a sudden death or died within 24 hours and around 15% were ill for between 1 day and 1 month.

Table 2: Services received in last 3 months of life

	percentage		
	Yes	No	Don't know or nil response
Stayed in			
– Hospital	63	21	16
– Hospice	16	62	22
– Care home	28	46	26
Service used (any setting)			
– Out of hours	42	16	42
– District/community nurse	50	2	47
– GP	73	5	23
Care delivered at home			
– Macmillan nurses	16	82	2
– Hospice at home	3	95	2
– Marie Curie	4	94	2
– Social worker/support worker	8	89	2
– Home care worker/aide/help	20	78	2

Figures may not add due to rounding

Table 3: Overall quality of care across all settings by age and other factors

N= 18,841: Around 16% of respondents did not know or gave a nil response.

	Number	Outstanding	Excellent	Good	Fair	Poor
All patients	18,841	12	30	33	14	10
Age						
<65	2,082	16	31	28	13	12
65-79	4,856	14	30	31	14	12
80+	11,903	11	30	36	15	8
Cause of death						
CVD	5,183	9	27	36	16	11
Cancer	6,197	16	35	30	11	8
Other	7,461	11	29	34	16	10
Place of death						
Home	3,712	19	34	29	10	7
Hospital	9,492	7	25	36	18	13
Care Home	4,357	15	36	32	12	5
Hospice	1,280	20	39	28	8	5
Gender						
Male	8,301	12	30	33	15	10
Female	10,540	13	30	34	14	9
Deprivation						
1	3,084	12	28	31	16	13
2	3,478	13	29	33	15	10
3	4,082	13	30	34	14	9
4	4,146	11	32	35	13	8
5	4,051	12	32	34	14	8

Figures may not add due to rounding

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For the overall quality of care across all services, 12% rated the care given as outstanding, 30% as excellent, 33% reported care as good, 14% as fair and 10% as poor. The highest proportions of ratings as outstanding were for patients who died in hospices (20%) and at home (19%) compared with 7% for hospitals, those who died of cancer (16% versus 9% for CVD and 11% other) and patients under 65 years (16% vs. 11% for those aged 80 or over).

Table 4: Quality of care - by services and care setting

	Number	Percentage			
		Excellent	Good	Fair	Poor
Out of hours	9,090	26	39	19	16
District/community nurses	8,973	45	37	11	6
GPs	14,740	35	37	17	11
Care homes	6,138	46	35	13	7
Hospital doctors	11,871	38	36	16	10
Hospital nurses	12,785	35	33	18	14
Hospices	2,207	78	14	5	4

Figures may not add due to rounding

Care was rated as excellent for 78% who had been in a hospice and as excellent or good by 92%. The combined 'excellent' and 'good' percentages for other care settings and services were as follows: Care homes 81%; district/community nurses 82%, hospital doctors 74%, GPs 72%, hospital nurses 68% and out of hours services 65%.

Table 5: Dignity and respect by services and care setting

	percentage			
	All of the time	Most of the time	Some of the time	Never
District/community nurses	79	15	4	2
GPs	72	17	9	2
Care homes	61	28	9	1
Hospital Doctors	57	27	15	2
Hospital Nurses	48	28	22	3
Hospice Doctors	87	8	3	2
Hospice Nurses	80	13	5	2

Figures may not add due to rounding

Being shown dignity and respect by staff was highest in hospices (87% “all of the time” for hospice doctors and 80% for hospice nurses); followed by district/community nurses (79%); GPs (72%); care home staff (61%); hospital doctors (57%) and hospital nurses (48%).

Table 6: Dignity and respect “all of the time” by services and care setting and by cause of death

	Cardiovascular	Cancer	Other	percentage p
DNs/Community nurses	74	83	75	<0.001
GPs	71	75	70	<0.001
Care homes	59	66	61	0.001
Hospital Doctors	56	58	56	n/s
Hospital Nurses	47	49	47	<0.01
Hospice Doctors	74	90	74	<0.001
Hospice Nurses	59	87	58	<0.001

Note: The numbers dying in a hospice where the reported underlying cause of death was other than cancer were small and therefore some caution should be taken when interpreting these numbers.

Dignity and respect ratings were generally highest for patients with cancer as the cause of death, though no significant difference by cause of death was observed among hospital doctors.

Table 7: Dignity and respect “all of the time” by services and care setting and by age at death

	Under 65	65–79 years	80 or older	percentage p
DNs/Community nurses	80	79	78	<0.001
GPs	70	73	72	<0.001
Care homes	71	61	61	<0.001
Hospital Doctors	56	57	57	<0.01
Hospital Nurses	52	49	46	<0.001
Hospice Doctors	89	88	83	<0.05
Hospice Nurses	84	85	72	<0.001

In care homes, dignity and respect ratings were highest for patients aged under 65 years compared with the older age groups. In the hospital setting, patients who died at 80 years or older were rated lowest compared with both the under 65 and 65 to 79 year age groups.

Table 8: Coordination of care (1)

“Community services worked well together”

N = 8,820. This excludes 15% who reported that no community care was received and 46% who gave a nil response or don't know.

	Number	Yes definitely	Yes to some extent	No	percentage p
All patients	8,820	45	42	14	-
CVD	1,859	40	45	15	
Cancer	4,278	50	39	12	
Other	2,683	40	44	16	<0.001
Place of death					
Home	3,018	58	34	8	
Hospital	4,122	37	45	17	
Care home	656	35	48	18	
Hospices	1,024	43	44	13	<0.001
Age at death					
<65 years	1,278	48	39	13	
65-79 years	2,703	47	38	14	
80+ years	4,839	42	44	14	<0.001

Figures may not add due to rounding

Coordination of community services was highest for those dying at home, those dying from cancer and those aged under 80 years.

Table 9: Coordination of care (2)

“Hospital services worked well together with GP and other services outside hospital”

N = 8,692. This excludes around 60% who said they did not know or gave a nil response.

	N	Yes definitely	Yes to some extent	No	percentage p
All patients	8,692	33	36	32	-
Cause of death					
CVD	2,091	32	35	33	
Cancer	3,464	36	36	28	
Other	3,137	31	35	35	<0.001
Place of death					
Home	1,579	39	36	25	
Hospital	5,021	33	34	33	
Care home	1,362	28	38	34	
Hospice	730	28	41	31	<0.001
Age at death					
<65 years	1,175	33	35	32	
65-79 years	2,488	33	35	32	
80+ years	5,029	33	36	31	n/s

Figures may not add due to rounding

Coordination of hospital services with external services was highest for those dying at home and for those dying from cancer. There were no differences by age at death.

Table 10a: Relief of pain and suffering in last 3 months of life by care setting

“How well was the pain relieved while at home / while in hospital / while in the care home / while in the hospice”

This excludes responses where the patient did not have any pain, where the respondent did not know or gave a nil response.

	Number	Completely – all of the time	Completely – some of the time	Partially	Not at all
Home	8,992	17	30	46	8
Hospital	9,837	36	30	29	4
Care home	4,303	45	29	24	3
Hospice	1,802	62	25	11	2

Figures may not add due to rounding

Pain relief was reported as being most effective in hospices and least effective at home.

Table 10b: Complete relief of pain and suffering all of the time in last 3 months of life by cause of death

	Cardiovascular	Cancer	Other	p
Home	11	21	13	<0.001
Hospital	36	35	37	<0.01
Care home	43	46	45	<0.02
Hospice	52	64	53	0.001

In hospices and at home relief of pain was reported to be highest for those who died of cancer. In hospitals and care homes relief of pain was similar across cancer, CVD and other causes of death.

Table 11a: Care and support in last 2 days of life

Location of decedent in last two days

	Number	Percentage
At home all the time	4,181	22
In a care home all the time	4,400	22
In a hospital all the time	7,934	44
In a hospice all the time	1,334	7
Other	741	4

Table 11b: Location in last 2 days by cause of death

	percentage				
	Home	Care home	Hospital	Hospice	Other
CVD	23	22	49	1	5
Cancer	33	11	33	20	3
Other	13	31	50	1	4

Figures may not add due to rounding

Hospital was the most common location for all cause of death groups.

Table 11c: Location in last 2 days by age at death

	percentage				
	Home	Care home	Hospital	Hospice	Other
<65 years	33	4	41	16	6
65-79 years	30	10	44	12	4
80+ years	16	32	45	3	4

Figures may not add due to rounding

The oldest age group (80+) were much more likely to be in a care home and least likely to be at home in the last 2 days of life.

Table 12: Dignity and respect in the last 2 days of life by place of death

	percentage			
	All of the time	Most of the time	Some of the time	Never
Doctors	75	15	7	3
– Home	84	7	3	6
– Hospital	67	20	10	3
– Care home	82	11	5	3
– Hospice	94	3	2	-
Nurses	73	16	9	3
– Home	86	8	3	4
– Hospital	63	21	13	3
– Care home	80	14	5	1
– Hospice	93	5	2	-

Figures may not add due to rounding

Ratings for doctors and nurses were broadly similar and for both doctors and nurses the highest ratings were where the patient died in a hospice. Ratings were similar for care from doctors and nurses where the patient died at home or in a care home. Ratings for hospital staff were lowest.

Table 13a: Help received in the last 2 days of life

	percentage				
	Strongly agree	Agree	Neither	Disagree	Strongly disagree
Personal care needs met	41	38	8	7	5
Nursing care needs met	42	37	9	7	5
Adequate privacy provided	49	33	6	6	5

Figures may not add due to rounding

The large majority of patients were reported to have had their personal needs met in the last two days of life (79% strongly agree or agree); to have had their nursing needs met (79%) and to have had adequate privacy (82%) However, a significant minority (5%) of respondents strongly disagreed on each of these items.

Table 13b: Help received in the last 2 days of life: strongly agree / agree by place of death

	percentage			
	Home	Hospital	Care Home	Hospice
Personal care needs met	83	71	89	96
Nursing care needs met	82	71	89	95
Adequate privacy provided	92	72	96	95

Ratings were lowest on all three areas of help received for those patients who died in hospital (71% personal needs, 71% nursing needs and 72% adequate privacy) and highest for those who died in a hospice (96%, 95% and 95% respectively).

Table 14: Support received in last 2 days of life

	percentage			
	Excellent	Good	Fair	Poor
Relief of pain	44	35	14	7
Relief of other symptoms	38	36	16	10
Spiritual support	38	29	13	19
Emotional support	40	31	14	15
Support to stay where they wanted to be	51	29	9	11

Figures may not add due to rounding

The large majority of respondents reported that support received in the last 2 days of life was excellent or good in relation to relief of pain (79%), relief of other symptoms (74%) and support to stay where they wanted to (80%). Ratings for emotional support (71%) and spiritual support (67%) were somewhat lower. These aspects of support also had the highest percentages of 'poor' support.

Table 15: Decisions made about care which patient would not have wanted

N= 19,215: Around 30% of respondents did not know or gave a nil response.

	Yes	No	Don't know	percentage p
All patients	17	64	19	-
Cause of death				
CVD	17	63	20	
Cancer	16	69	15	
Other	19	60	21	<0.001
Place of death				
Home	10	76	14	
Hospital	20	58	21	
Care home	19	63	19	
Hospice	15	73	12	<0.001
Age at death				
<65 years	14	66	20	
65-79 years	16	64	20	
80+ years	19	63	18	<0.001

Figures may not add due to rounding

Overall, respondents reported that decisions were made about care which the patient would not have wanted in around 17% of cases. The percentage reporting 'yes' was lowest for patients who died at home and those aged less than 80 years. There was little difference across cause of death.

Table 16: Patient involved in decisions about their care as much as wanted

N= 15,315: Around 32% of respondents did not know or gave a nil response.

	Yes	Preferred more involvement	Preferred less involvement	p
				percentage
All patients	85	14	1	-
Cause of death				
CVD	84	15	1	
Cancer	88	11	1	
Other	84	15	1	<0.001
Place of death				
Home	92	7	1	
Hospital	82	18	1	
Care home	86	13	1	
Hospice	89	10	1	<0.001
Age at death				
<65 years	85	15	1	
65-79 years	85	15	1	
80+ years	86	13	1	n/s

Figures may not add due to rounding

The large majority of patients (84%) were involved in the person's care as much as they wanted, with very few reporting that they would have preferred less involvement. Involvement was highest for those who died at home (92%) and for those who died of cancer (88%). There were no significant differences by age at death.

Table 17: Did the patient know they were likely to die?

N= 18,035: Around 19% of respondents were unsure or gave a nil response.

	Yes definitely	Yes probably	Probably not	No definitely	percentage p
Overall	32	29	22	17	-
Cause of death					
CVD	15	28	26	30	
Cancer	62	25	8	5	
Other	21	33	29	18	<0.001
Place of death					
Home	47	21	14	19	
Hospital	23	31	25	20	
Care home	28	34	26	13	
Hospice	74	20	4	2	<0.001
Age at death					
<65 years	45	19	14	23	
65-79 years	39	24	17	20	
80+ years	26	34	26	15	<0.001
Reported duration of illness					
<24 hours	4	9	25	62	
1 day- <1 month	14	29	33	24	
1 month - <6 months	37	33	20	11	
6 - <12 months	45	32	15	8	
12 months or more	39	30	20	11	<0.001

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Overall, a minority of patients knew they were going to die (32%). The proportion of patients who were reported as definitely knowing they were likely to die was much higher for cancer patients.

Table 18: Patient told they were likely to die in a sensitive way.

N= 5,858: Note around 74% did not respond: [12 per cent Don't Know; 12 per cent Not apply – didn't know patient was dying; 36 per cent Not apply – patient not told and 14 per cent Nil response].

	Number	Yes definitely	Yes to some extent	No, not at all	percentage p
Overall	5,858	59	29	12	
Cause of death					
CVD	855	56	31	13	
Cancer	3,661	60	29	12	
Other	1,342	61	26	13	0.05
Place of death					
Home	1,759	60	27	12	
Hospital	2,273	54	32	15	
Care home	903	69	24	8	
Hospice	923	63	27	10	<0.001
Age at death					
<65 years	1,097	55	30	15	
65-79 years	2,044	58	30	12	
80+ years	2,717	63	26	11	<0.001

Figures may not add due to rounding

Most respondents considered that the patient had been told in a sensitive way. This did not vary significantly by cause of death. Older people (aged 80+) were most likely to have been told in a sensitive way. There were no significant differences between those who died in care homes, hospices and in their own homes.

Table 19: Had the patient expressed a preference of where they wanted to die?

N= 19,888: 11% gave a nil or invalid response.

	Yes	No	Not sure	percentage p
Overall	44	52	5	-
Cause of death				
CVD	36	60	5	
Cancer	59	37	4	
Other	38	58	5	<0.001
Place of death				
Home	67	30	4	
Hospital	36	59	5	
Care home	35	60	5	
Hospice	61	36	4	<0.001
Age at death				
<65 years	48	47	5	
65-79 years	47	49	4	
80+ years	41	54	5	<0.001

Figures may not add due to rounding

Overall, somewhat less than one half of all patients were reported to have expressed a preference of where they would like to die.

The proportion was highest for cancer patients and those who died at home. The proportion was reported to be lowest among people over 80 years.

For those who had expressed a preference, most (71%) preferred to die at home.

Table 20: Did the patient have enough choice about where they might die

N= 13,238:16% nil response and 26% said the patient died suddenly.

	Yes	No	Not sure	percentage
All	51	23	26	-
Cause of death				
CVD	41	28	31	
Cancer	65	16	19	
Other	42	27	31	<0.001
Place of death				
Home	88	5	7	
Hospital	29	35	36	
Care home	53	21	27	
Hospice	70	12	18	<0.001
Age at death				
<65 years	58	22	19	
65-79 years	54	23	23	
80+ years	48	24	29	<0.001

Figures may not add due to rounding

Choice was reported to be highest for cancer patients than others and was much higher for those dying at home or in hospices than for those dying in hospitals. Having enough choice was lower among older people (80+ years).

Table 21: Respondent thought patient died in the right place

N= 19,761: Around 12% gave a nil or invalid response.

	Yes	No	Not sure	percentage
Overall	82	10	8	-
Cause of death				
CVD	80	11	9	
Cancer	85	9	6	
Other	81	11	8	<0.001
Place of death				
Home	94	3	3	
Hospital	73	16	11	
Care home	88	7	6	
Hospice	93	3	4	<0.001
Age at death				
<65 years	78	12	9	
65-79 years	80	12	8	
80+ years	83	9	7	<0.001

Figures may not add due to rounding

The large majority (82%) of respondents felt that the patient had died in the right place. This was most likely to be reported for patients who died at home (94%) or in a hospice (93%) and least likely for those dying in hospital, but still relatively high at 73%.

Table 22: Support for carers in the last 3 months of life for those at home

N= 11,269:41% gave a nil response and a further 9% said that help was not needed.
percentage

	Yes - as much as wanted	Yes – some but more wanted	No but tried to get help	Didn't ask for help	p
Overall	50	20	15	15	-
Cause of death					
CVD	45	21	16	18	
Cancer	57	19	13	11	
Other	45	20	18	16	<0.001
Place of death					
Home	66	16	9	9	
Hospital	41	21	19	19	
Care home	46	24	20	11	
Hospice	56	23	13	8	<0.001
Age at death					
<65 years	49	20	16	15	
65-79 years	51	18	16	15	
80+ years	50	21	15	14	<0.01

Figures may not add due to rounding

Carers of cancer patients and of those who died at home or in a hospice were most likely to report having had as much support from health and social services as they wanted.

Table 23: Respondent able to discuss worries and fears with the GP

N=14,083: Almost a third (30%) gave a nil response and 7% said they had no worries or fears to discuss.

	percentage				p
	Yes - as much as wanted	Yes – some, but more wanted	No but tried to discuss	Didn't try to discuss	
Overall	56	17	8	19	-
Cause of death					
CVD	54	16	9	21	
Cancer	60	17	7	17	
Other	55	17	8	19	<0.001
Place of death					
Home	70	13	6	12	
Hospital	50	18	10	22	
Care home	58	17	6	19	
Hospice	60	17	6	17	<0.001

Figures may not add due to rounding

Respondents for patients who died of cancer and those who died at home were most likely to report that they were able to discuss their worries and fears as much as they wanted with their GP.

Younger respondents (age <60 years) were less likely to report being able to discuss worries and fears as much as they wanted with the GP (49% compared with 63% in those 60 years and over).

Table 24: Respondent involved in decisions about person's care as much as wanted.

N=18,464: 4% didn't know 14% nil response.

	Yes	Preferred more involvement	Preferred less involvement	percentage p
Overall	78	22	-	-
Cause of death				
CVD	77	23	-	
Cancer	79	21	-	
Other	77	23	-	n/s
Place of death				
Home	84	16	-	
Hospital	71	29	-	
Care home	86	14	-	
Hospice	82	18	-	<0.001

Figures may not add due to rounding

The large majority of respondents (78%) were involved in the person's care as much as they wanted, with very few reporting that they would have preferred less involvement. There was no significant difference by cause of death. Sufficient involvement was lowest (71%) among those where the patient died in hospital.

Younger respondents (under 60 years) were more likely to report that they would have wanted more involvement (27% compared with 18% in those 60 years and over).

Table 25: Support for respondent/family adequate at the time of the death.

N= 18,673: 16% gave a nil response or said they did not know.

	Yes definitely	Yes to some extent	No, not at all	percentage p
Overall	59	27	14	-
Cause of death				
CVD	55	28	16	
Cancer	65	24	11	
Other	57	28	15	<0.001
Place of death				
Home	60	22	18	
Hospital	53	31	15	
Care home	64	25	11	
Hospice	85	12	2	<0.001

Figures may not add due to rounding

Around three in five respondents reported that they/their family received adequate support at the time and following death. This was much higher (85%) among respondents of those who died in a hospice.

Younger respondents were less likely to report having received adequate support (54% compared with 63% in those 60 years and over).

Table 26: After the patient died did the staff deal with you or the family in a sensitive manner?

N= 18,159: 19% gave nil responses, did not know or had no contact with staff.

	Yes	No	percentage p
Overall	93	7	-
Cause of death			
- CVD	93	7	
- Cancer	95	5	
- Other	93	7	<0.001
Place of death			
- Home	94	6	
- Hospital	91	9	
- Care home	96	4	
- Hospice	99	1	<0.001

Figures may not add due to rounding

The large majority (93%) of respondents reported that they had been dealt with in a sensitive manner after the patient died, with a particularly high proportion (99%) for respondents of those who died in a hospice.

Table 27: Did respondent talk to anyone from health or social services or from a bereavement service since the death – and would they have wanted to?

N= 19,149: Around 14% gave a nil or invalid response or stated they were not sure.

	Yes	No, but would have liked to	No, did not want to	p
Overall	15	19	67	-
Cause of death				
CVD	12	18	70	
Cancer	21	18	60	
Other	11	19	70	<0.001
Place of death				
Home	18	18	64	
Hospital	14	21	65	
Care home	8	15	77	
Hospice	31	12	57	<0.001

Figures may not add due to rounding

Around two thirds of respondents did not want to talk to anyone from health or other services after death.

Respondents of those who died in a hospice were the most likely to have talked to someone after the death.

Younger respondents and female respondents were more likely to have wanted to talk to someone after the death. (Of those under 60 years, 23% compared with 15% of those aged 60 years or over and 21% of female respondents compared with 15% of male respondents).

Table 28: Variations by PCT cluster

	England	Lowest PCT cluster	Highest PCT cluster	percentage Difference
Overall quality of care across all services (“Outstanding / Excellent”)	43	32	51	19
Community services worked well together while patient at home - “yes – definitely”	45	35	54	19
Hospital services worked well with GP and other community services	33	24	46	22
Dignity and respect shown ‘all the time’ by doctors in the last 2 days of life	75	67	83	15
Dignity and respect shown by nurses ‘all the time’ in the last 2 days of life	73	64	80	16
Relief of pain in last 2 days of life “Excellent”	44	30	53	22
Patient was involved in decisions about care as much as wanted in last 3 months of life	85	80	91	12
The patient expressed a preference of where they would like to die	44	38	50	11
Respondent considered patient died in the right place	82	77	85	8
Support for carers while patient at home – ‘as much as wanted’	50	41	65	25
Support for carers: carers able to discuss their worries or fears with the GP	56	43	66	23

See web Appendix A for details of all PCT Clusters for all 11 key questions, shown as benchmarking charts. The highest scoring 20% of PCT Clusters are shown in green, the lowest scoring 20% of PCT Clusters are shown in red and amber shows the remaining 60%. A summary table of PCT Clusters is shown below (Table 29). Note that numbers for Inner North East London were too low to reliably determine a rating.

Table 29: Summary table of benchmark ratings for PCT Clusters across 11 key questions

	A1	A2	A3	A4	A5	A6	A7	A8	A9	A10	A11
NORTH EAST											
Durham and Darlington	Red	Yellow	Green	Yellow	Green	Green	Green	Yellow	Yellow	Green	Yellow
North of Tyne	Green	Green	Green	Green	Green	Green	Yellow	Red	Green	Green	Green
South of Tyne and Wear	Yellow	Yellow	Yellow	Green	Green	Green	Green	Red	Yellow	Yellow	Yellow
Tees	Yellow	Green	Yellow	Yellow	Yellow	Green	Red	Green	Yellow	Green	Yellow
NORTH WEST											
Cheshire, Warrington and Wirral	Green	Green	Yellow	Yellow	Green	Yellow	Green	Red	Green	Green	Yellow
Cumbria	Green	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Green
Greater Manchester	Yellow	Red	Yellow	Yellow	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Yellow
Merseyside	Yellow	Yellow	Yellow	Green	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Red
Pan-Lancashire	Yellow	Red	Red	Red	Red	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow
YORKSHIRE & THE HUMBER											
Bradford and Airedale	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Red	Red	Yellow
Humber	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Red	Yellow	Red
Leeds	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Red	Red	Yellow	Yellow	Yellow
North Yorkshire & York	Green	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Green	Yellow
South Yorkshire	Yellow	Red	Red	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Yellow	Yellow
West Yorkshire	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Yellow
EAST MIDLANDS											
Derbyshire	Yellow	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Yellow
Leicestershire	Yellow	Yellow	Red	Red	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow
Lincolnshire	Red	Yellow	Red	Red	Red	Red	Yellow	Yellow	Red	Red	Yellow
Milton Keynes and Northamptonshire	Yellow	Yellow	Red	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Yellow	Yellow
Nottingham	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Yellow	Yellow
WEST MIDLANDS											
Arden	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Yellow
Birmingham	Yellow	Red	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Red	Red	Yellow
Black Country	Red	Yellow	Yellow	Red	Red	Red	Red	Yellow	Yellow	Red	Yellow
Staffordshire	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Yellow	Green	Yellow
West Mercia	Green	Green	Yellow	Green	Yellow	Green	Yellow	Red	Yellow	Yellow	Yellow
EAST OF ENGLAND											
Bedfordshire and Luton	Red	Yellow	Red	Yellow	Red	Red	Red	Yellow	Yellow	Yellow	Green
Cambridgeshire and Peterborough	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Green	Green	Green
Hertfordshire	Red	Yellow	Yellow	Red	Red	Red	Red	Yellow	Yellow	Red	Yellow
Norfolk, Great Yarmouth and Waveney	Yellow	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Green	Green	Yellow	Yellow
North Essex	Yellow	Red	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Red
South Essex	Red	Yellow	Yellow	Red	Red	Red	Yellow	Green	Yellow	Yellow	Red
Suffolk	Yellow	Yellow	Green	Yellow	Green	Yellow	Green	Green	Yellow	Yellow	Green
LONDON											
Inner North East London	Grey	Grey	Grey	Grey	Grey	Grey	Grey	Grey	Grey	Grey	Grey
North Central London	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Red
North West London	Red	Red	Yellow	Red	Red	Yellow	Red	Red	Red	Red	Red
Outer North East London	Red	Red	Red	Red	Red	Red	Red	Red	Red	Red	Red
South East London	Red	Red	Red	Red	Red	Red	Red	Red	Red	Red	Red
South West London	Yellow	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Yellow	Yellow	Red	Red
SOUTH EAST COAST											
Kent and Medway	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow
Surrey	Yellow	Yellow	Red	Yellow	Yellow	Yellow	Red	Red	Yellow	Yellow	Yellow
Sussex	Yellow	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Yellow
SOUTH CENTRAL											
Berkshire	Red	Red	Yellow	Yellow	Yellow	Red	Yellow	Yellow	Red	Yellow	Red
Buckinghamshire and Oxfordshire	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Green	Yellow	Green
Southampton, Hants, Isle of Wight & Portsmouth	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow
SOUTH WEST											
Bath & North East Somerset and Wiltshire	Yellow	Yellow	Yellow	Green	Yellow	Yellow	Green	Green	Yellow	Green	Green
Bournemouth and Poole and Dorset	Green	Green	Green	Green	Green	Green	Yellow	Yellow	Yellow	Yellow	Green
Bristol, North Somerset & South Gloucestershire	Green	Yellow	Yellow	Green	Yellow	Green	Green	Yellow	Yellow	Yellow	Yellow
Devon, Torbay and Plymouth	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Swindon and Gloucestershire	Yellow	Yellow	Yellow	Yellow	Yellow	Red	Green	Red	Yellow	Yellow	Yellow
Somerset	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Cornwall and Isles of Scilly	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow

A1. Overall quality of care across all services by PCT Clusters	A6. Pain management in the last two days
A2. Co-ordination of care while patient was at home	A7. Patient involved in decisions re: care as much as wanted
A3. Co-ordination of care: hospital with GP/community services	A8. Patient expressed preference where would like to die
A4. Dignity & Respect shown by doctors all of the time last 2 days	A9. Respondent considered patient died in the right place
A5. Dignity & Respect shown by nurses all of the time last 2 days	A10. Support for carers while patient at home
	A11. Support for carers able to discuss worries with GP

Table 30a: Overall quality of care across all settings by dementia

	Number	Outstanding	Excellent	Good	Fair	Poor
No mention	14,471	12	30	33	15	10
Dementia	4,370	14	32	34	12	7

Respondents of patients where dementia was mentioned were more likely to rate the overall quality of care as outstanding or excellent compared with those without, and were less likely to rate the overall quality of care as poor.

Table 30b: Quality of care by settings by dementia

	Number	Excellent	Good	Fair	Poor
GPs					
No mention	11,622	35	36	17	12
Dementia	3,118	33	43	16	8
Care Homes					
No mention	3,118	43	34	14	8
Dementia	3,020	48	35	11	5
Hospital Doctors					
No mention	9,904	39	35	16	10
Dementia	1,967	32	39	18	11
Hospital Nurses					
No mention	10,565	37	32	18	14
Dementia	2,220	29	35	19	17

Table 30c Dignity and respect by services and settings by dementia

	Number	All of the time	Most of the time	Some of the time	percentage Never
GPs					
No mention	11,499	72	17	9	2
Dementia	2,949	74	18	7	2
Care Homes					
No mention	3,143	59	29	11	2
Dementia	2,988	64	27	8	1
Hospital Doctors					
No mention	9,662	57	26	15	2
Dementia	1,893	54	28	15	3
Hospital Nurses					
No mention	10,463	49	27	21	3
Dementia	2,156	43	29	25	4

Respondents of patients where dementia was mentioned were more likely to rate the quality of care from GPs as good compared with those without, and were less likely to rate the quality of GP care as poor. There was little difference for the dignity and respect shown by GPs for the patient groups.

A similar picture was found for care homes. Respondents of patients where dementia was mentioned were more likely to rate the quality of care as excellent compared with those without, and were less likely to rate the quality care as poor. Respondents were more likely to rate that dignity and respect was shown all the time by care home staff to patients with dementia compared with those without.

While respondents of patients where dementia was mentioned were less likely to rate the quality of care from hospital staff as excellent compared with those without, they were also more likely to rate the care as good. Respondents were less likely to rate that dignity and respect was shown all the time to patients with dementia compared with those without by hospital staff.

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