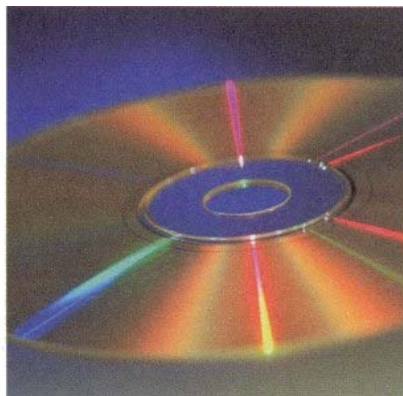
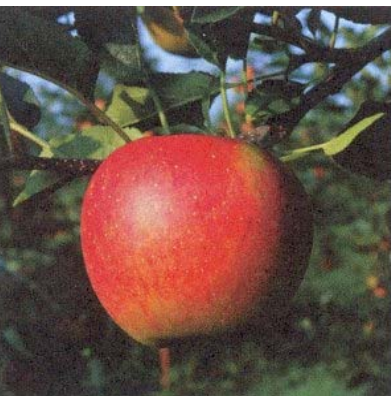


Results of the 2008/2009 Hospice Patient Survey

General Report

Commissioned by Help the Hospices



Charlotte Hastie, Linda Jenkins and
Jan Codling

August 2009



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Results of the 2008/2009 Hospice Patient Survey

General Report

**Charlotte Hastie and Linda Jenkins,
Health and Social Survey Unit, CHSS, University of Kent
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We would like to thank Help the Hospices and the 52 Hospices who funded the study and agreed to take part in the survey, to whom we are grateful. We would also like to thank all the patients who took part in the survey.

We would also like to thank Nick Pahl, former Development Director at Help the Hospices, for his work and support in setting up this series of surveys.

Executive Summary

- The 2008/09 survey is the third in a series of surveys on patient satisfaction with inpatient and daycare services carried out by Help the Hospices and the Centre for Health Services Studies at the University of Kent, with previous surveys being completed in 2004/05 and 2006/07. All hospices across the UK were invited to take part in the 2008/09 Patient Survey and 52 hospices participated between July 2008 and February 2009.
- The method of data collection was a self-completion questionnaire, with one questionnaire for adult users of daycare services and another for inpatient services. Each hospice distributed a questionnaire and an accompanying information letter to inpatients at discharge and to daycare patients at discharge or after two months of attending daycare. The survey included respite patients, those being discharged for terminal care at home, and readmissions even though the latter group may have been given the opportunity to complete the questionnaire more than once.
- There were 2222 replies, 1259 from daycare users and 963 from inpatients. For the 50% of hospices that supplied sufficient details on distribution, there was an overall response rate of 62% for daycare, and 41% for inpatients. Results are shown separately for the two services, and as well as the figures for all hospices, the report gives the results for hospices that achieved the benchmark figure of 40 responses.
- Results in 2008/9 were similar to the previous survey with the many patients expressing high levels of satisfaction with the services they received.
- Regarding the information hospices supply their patients, it was quite common for patients to say they had not seen or could not remember any leaflet or information booklet, and, for daycare patients, levels of awareness had fallen since the last survey. Those that received written information found it helpful and easy to read. A number of comments were made about the information, such as pointing out where it was out of date or unclear, and making suggestions as to what could be added.
- Daycare patients were asked how anxious they were at the beginning and end of their first visit, and reported a sharp drop in anxiety by the end of their first day.
- Respondents were overwhelmingly positive in their comments about staff, and the caring role that the hospices as a whole provided. On the specific question of whether staff introduced themselves to patients and explained what they were doing, this was not always the case. Patients said they had confidence in the staff, and this was especially so for daycare services. Patients were satisfied with their involvement with planning their care, and this area had improved since the last survey. Not everyone understood explanations about care.
- Patients usually felt able to ask questions when they wanted to. Some (inpatients) said they did not always have time to make decisions about their care, and that staff did not always make an effort to meet their individual needs, however, they felt they were treated with respect. Only two thirds said they knew how to register a complaint, and for inpatients the proportion who knew had fallen.
- Daycare patients were asked about the transport service, which nearly three quarters of them used. They rated its punctuality, comfort and safety highly, and outlined some of the specific difficulties they had when using the vehicles. Both inpatients and daycare patients rated hospices highly on cleanliness, and for the general environment, but less highly for catering, access to food for inpatients, and activities available to daycare patients. Although compared to the last survey, ratings on these facilities had gone up for inpatients, the specific comments made on catering, the available activities and premises are likely to be of help to hospices.

- Inpatients were aware of how to call for help and were fairly satisfied with the response. Daycare patients generally felt that there were enough staff or volunteers around to offer help if needed.
- The proportion who said they felt extremely supported after the death or discharge of another patient or group member was not very high, and had gone down for daycare users since the last survey. A few, and these were more likely to be daycare patients, felt totally unsupported after a group member's death or discharge.
- It is recommended that participating hospices develop their own action plans where there is scope for improvement, identified from their individual results.

1. Introduction

Welcome to the third Hospice Patient Survey coordinated by Help the Hospices in conjunction with the Centre for Health Services Studies at the University of Kent. This report details the findings for the 52 Hospices that participated in the survey between 1st July 2008 and 28th February 2009.

Since its original conception in 2003, the Hospice Patient Survey has evolved, incorporating information from two pilot studies and feedback from many stakeholders, including hospices and service users. Fundamentally the requirement was for a questionnaire which would fulfil the obligation that Hospices have under the National Minimum Standards for Independent Healthcare (2002) Standard C6 *'A patient survey is carried out annually, as a minimum to seek the views of patients on the quality of the treatment and care provided, whilst also presenting the opportunity for hospices to participate in a national benchmarking scheme.*

Views of hospice service users were sought to ensure clarity and ease of completion and the plain English "Crystal Mark" was also achieved in 2006. The resulting questionnaire was to be anonymous and incorporated questions relating to information giving, staff attitudes, involvement in care planning, confidence in staff, privacy and courtesy, catering and hygiene, and awareness of the process for making a complaint.

The target audience for the questionnaire are people who have palliative care needs and have accessed hospice care either through the inpatient or day therapy service. The questionnaire is circulated to those individuals who are discharged from either service and to those who have used the day therapy facilities for a period of greater than two months. The questionnaires are returned in a prepaid envelope to and analysed by the Centre for Health Services Studies at the University of Kent.

An overall Patient Survey report is produced and analysis is made available in a benchmarking format for those hospices where 40 or more questionnaires are returned from a service. This allows individual hospices to compare their results with other hospices, in a manner which is statistically valid.

Jan Codling
Chair – Help the Hospices Patient Survey Group
Head of Clinical Governance St Ann's Hospices, Manchester.

Jo Blackburn
Director of Practice Development, Help the Hospices.

2. The Background of Hospice Care

The idea of caring for people at the end of life has been developed over thousands of years, but since the opening of the first modern hospice, St Christopher's, South London, in 1967, the hospice movement has made rapid medical and social advances and has grown into a worldwide movement that has radically changed approaches to the way people are cared for when faced with terminal illness. It has been regarded by some as one of the greatest social innovations of the last hundred years.¹ Alongside local charities, national cancer charities Macmillan Cancer Support (formally Macmillan Cancer Relief) and Marie Curie Cancer Care have played a major role in the development of hospice and palliative care, contributing to funding, provision of services, education and research. Help the Hospices is the leading charity helping to support its member hospices and improve hospice care in the UK and across the world.²

Currently a quarter of a million patients are cared for by hospices in the UK each year, either in a hospice or in their own home³. Hospice care is a way of caring which aims to help people live as actively as possible after diagnosis to the end of their lives. The highest value is put on respect, choice and empowerment.⁴ The kind of care given in hospices is also known as palliative care; the World Health Organisation definition of palliative care is *an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*. The majority of hospice and palliative care is provided by charitable hospices, and donations and legacies contribute 53% of funding for adult hospices⁵. Some palliative care is carried out by the NHS and there is a closer partnership has emerged between the voluntary and NHS services.

Hospice care and the services hospices provide are:

- for those individuals whose illness may not be curable, predominately cancer but increasingly other life-limiting illnesses. These include neurological conditions (e.g. Motor Neurone Disease), Multiple Sclerosis, HIV/AIDS and heart and lung conditions,
- enabling patients to achieve the best possible quality of life,
- extends beyond the patient, to supporting family and close friends,
- considering the whole person and their physical, emotional, spiritual and social needs,
- trying to meet the needs of people from all cultures and communities.

UK services for adults include 220 hospice and palliative care inpatient units, 3217 hospice and palliative care beds and 282 daycare centres. Admission as an inpatient in a hospice care unit can be at the early stages of an illness for short periods of intensive care followed by ongoing support. Alternatively it may be required for rehabilitation after treatment, for control of symptoms, respite care, or terminal care for patients who are in the very final stages of their illness. A typical length of stay in an inpatient unit is between 10 to 14 days, after which they will then return to their home or other care setting. Provision of daycare services enables many patients to continue living at home while having access to hospice facilities. Daycare services may include medical and nursing care, rehabilitation, creative therapies and complementary therapies, as well as providing a range of other services and activities within a place where people have the opportunity to meet others in a similar

¹Help the Hospices. *Help the Hospices and the UK hospice movement – general information*. Help the Hospices; July 2008.

² Help the Hospices. *Hospice and Palliative Care Directory – UK and Ireland 2009-2010*. London: Help the Hospices; 2009.

³ <http://www.helpthehospices.org.uk/about-hospice-care>. 26/06/2009

⁴ Help the Hospices. *Hospice and Palliative Care Directory – UK and Ireland 2009-2010*. London: Help the Hospices; 2009.

⁵ Help the Hospices. *Help the Hospices and the UK hospice movement – general information*. Help the Hospices; July 2008

situation. Hospice inpatient services and daycare services, which are the focus of this survey, are just two types of service provision available to the public, others include hospital support services and home care provided by community palliative care nurses and 'Hospice at Home' services.⁶ In addition to the ethos of hospice care of the patient, hospice services also try to care for the family as well as the person who is ill. This help may include emotional and practical support, counselling services, complementary therapies and bereavement support.⁷

⁶ Help the Hospices. *Hospice and Palliative Care Directory – UK and Ireland 2009-2010*. London: Help the Hospices; 2009.

⁷ Help the Hospices. *Caring for someone with a terminal illness – some facts and figures*.

3. Methods

The 2008/09 survey is the third in a series of surveys on patient satisfaction with inpatient and daycare services carried out by Help the Hospices and the Centre for Health Services Studies, with previous surveys being carried out in 2004/05 and 2006/07. As in the previous surveys the method of data collection was by self-completion questionnaire, as this enabled the collection of a large number of responses at relatively low cost. One questionnaire was designed for the evaluation of daycare services and another for evaluation of inpatient services for adults (Appendix A and B). Some small amendments were made to these surveys which are outlined in Appendix C.

All hospices across the UK were invited by letter to take part in the 2008/09 Patient Survey. 52 hospices participated in the survey, one less than the previous two surveys. More hospices had registered an interest in participating but were unable to take part at this time. In total 46 hospices participated in daycare and 46 participated in the inpatient survey.⁸ Some of these hospices participated in both and some took part in just one service. This time 40 hospices distributed questionnaires to both daycare services and inpatient services, 6 distributed questionnaires to patients using daycare services only, and a further 6 hospices distributed to inpatient services only. Therefore the overall number of hospices participating in both services and in daycare was slightly less than the previous surveys but there was a slight increase in the number of hospices only participating in one service. Hospices invited that did not take part in the survey have their own method of measuring patient satisfaction in their hospice or they had the option to use the questionnaires from the 2008/09 patient survey but administer it themselves. The results for these hospices are not included in this report.

In preparation for the distribution of the survey each hospice was given a guidance sheet with detailed instructions of appropriate procedures, including start and end date, inclusion and exclusion criteria, informing patients of the survey and how to return it. When distributing the questionnaires, hospice staff were asked to reassure patients that the survey was anonymous and the staff giving the care would not see the completed questionnaire; and to say that patients were under no pressure to complete the survey and it would have no effect on their future care.

The survey was distributed to all adult patients in the participating hospices using inpatient and/or daycare services. This included respite patients and patients being discharged for terminal care at home, as their condition may unexpectedly change and they may still appreciate the opportunity to express their views. Readmissions were also given the opportunity to complete the questionnaire for a second time. For patients with visual impairment, audio versions of the questionnaires were available on request, and the use of interpreters was encouraged if required. Carers of patients were allowed to complete the survey on behalf of patients if required, however the views recorded had to be the views of the patient and not those of the carer. It is possible that some patients may not have been given a questionnaire based on clinical judgement due to reasons of altered consciousness or altered cognitive ability of the patient.

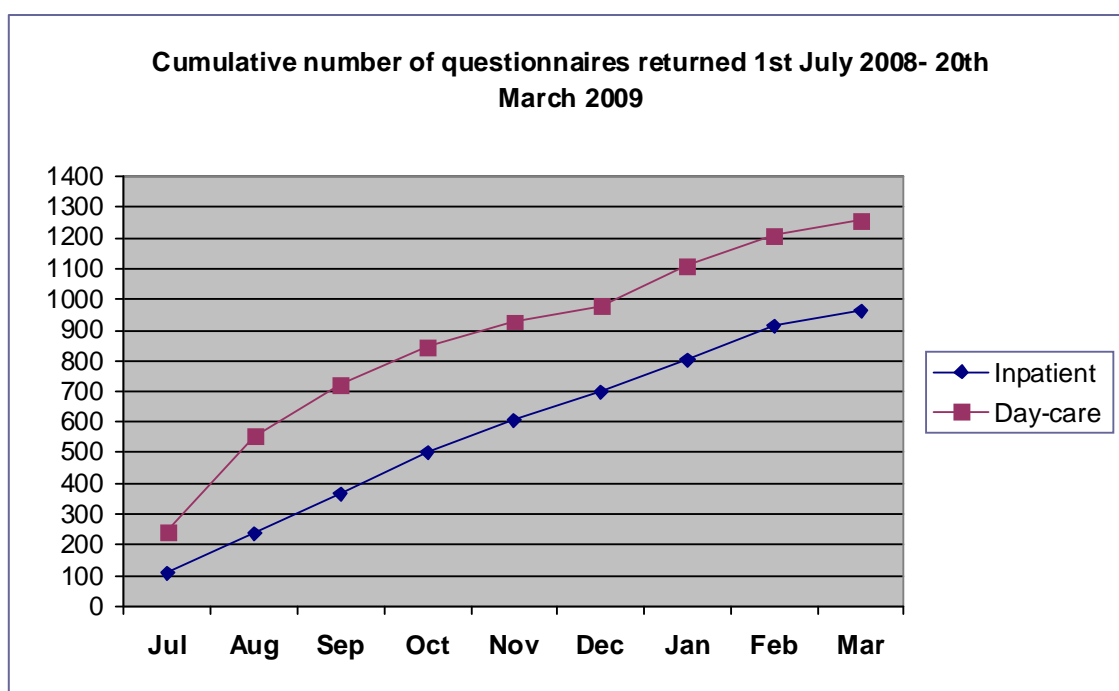
Participating hospices distributed questionnaires and an accompanying information letter to their own patients by printing off electronic copies and distributing them to inpatients at discharge and to daycare patients at discharge or after two months of attending daycare. The benefit of individual hospices printing off electronic copies was that hospices could tailor the instructions and style to fit their hospice and it enabled them to re-format the survey to help patients with visual impairments. It also allowed hospices to personalise the questionnaire by having it on different coloured paper, with their logo, and tailor certain information questions where indicated e.g. by included the name of the hospice, or to say whether they provided a leaflet or booklet when providing written information about their services. In order to ensure validity and prevent any bias in the answers given through inhibited responses, patients were encouraged to fill in the questionnaires at home rather than 'on the spot'.

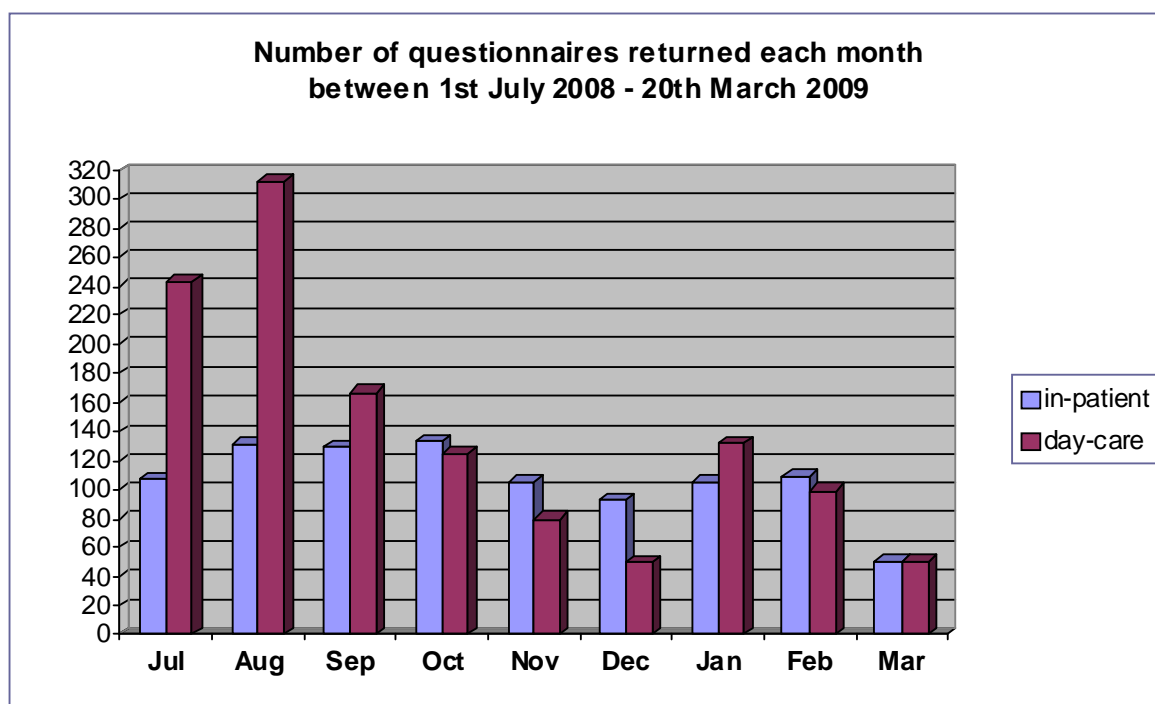
⁸ Results are not reported for one of the 46 hospices in the overall results and textual comments for daycare as the questionnaire used was significantly adapted and not easily comparable.

Patients were asked to return their completed questionnaires, which were anonymous, in the pre-paid envelope provided to a third party organisation and not to the hospice themselves. The third party organisation was the Centre for Health Services Studies, based at the University of Kent, who also carried out the analysis and reporting the survey in their Health and Social Survey Unit. By using the approach of an independent third-party rather than the hospice themselves to return the questionnaire, it was hoped that response rates would be higher as patients may be less anxious about participating if they knew the questions would not be seen and analysed within the hospice where they may return for care.

Following experiences of the previous two patient surveys the time frame for distribution and return of questionnaires was scheduled for eight months, between July 2008 and February 2009. A target of 40 completed questionnaires returned from one or both services was considered enough as a 'benchmark' figure. This figure was decided upon during the course of the 2004/05 survey as reaching a response higher than 40 was difficult for the vast majority of hospices. Although it was encouraged for statistical reasons, the ability to achieve the benchmark depended on the size of the hospices involved. Smaller hospices found it more difficult to achieve the benchmark of 40 or more completed questionnaires as they give care to a more limited number of patients whereas larger hospices stood a better chance of reaching the benchmarking figure. It was therefore not compulsory for all the hospices taking part to reach the benchmark.

The tables below show the frequency at which the questionnaires were returned each month over the eight-month period. Questionnaires were accepted up until mid to late March to allow for return of questionnaires distributed in late February at the end of the distribution period. As expected the number of questionnaires returned was lower for inpatient services (963) compared to daycare services (1259), probably due to the lower number of patients using these services. The number of responses from both services has decreased slightly compared to the previous survey but this is due to the slight difference in balance between the number of inpatient and daycare services taking part in each survey (Appendix D).





Overall the rate at which questionnaires were returned was steady for inpatients, whereas returns from daycare units were particularly high during the first months of data collection in July and August and then particularly low in December possibly due to the Christmas period. The high numbers and then the decrease in returns for Daycare is due to the reducing number of patients who fit the criteria, as many Daycare patients regularly using the service would have already received the questionnaire. For the actual numbers returned by individual participating hospices see Appendix E. As mentioned previously the number of responses received can depend on the size of the hospice, information on the size of individual hospice daycare and inpatient units is available in the annual UK Hospice and Palliative Care Directory.⁹ Some hospices fed back the number of questionnaires distributed during the 8 month period. From the information provided the overall response rate for the survey was 62% for daycare (from 25 hospices) and 41% for inpatient (from 25 hospices). In comparison to the response from the previous survey (based on information from 28 hospices for daycare and 29 hospices for inpatient) the results are similar for daycare but response has decreased by 8% from inpatients (Appendix D). However we can not be certain this is a true reflection of overall response to the survey with only 50% of hospices providing the relevant information.

The collected data was entered and analysed, generating descriptive statistics, using SPSS software versions 16 and 17 (Statistical Package for the Social Sciences). Open ended and textual comments were entered and analysed separately using Microsoft Excel.

⁹ Help the Hospices. *Hospice and Palliative Care Directory – UK and Ireland 2009-2010*. London: Help the Hospices; 2009. The directory is also available to search online at: <http://www.helpthehospices.org.uk/our-services/information-service/uk-hospice-and-palliative-care-services/?locale=en> 02/07/09

4. Results: Daycare

This section includes the results of the survey for daycare patients.

4.1 Individual Hospice Daycare Results

Individual hospice results are included in the reports given to each participating hospice.

4.2 Benchmark Daycare Results (9 hospices)

Nine hospices reached the benchmark figure of a minimum of 40 returned daycare questionnaires and are included in these benchmark results representing 436 patient views. This section of the report gives an overview of the aggregate results of these hospices by presenting the results in tables, charts and in a written commentary of the findings for each area covered by the survey including provision of information about services, anxiety when first visiting daycare, use of transport, staff communication and care, user involvement and understanding, views of users on support and respect they receive from staff, views on facilities and services.

The results, in table form, report the average patient responses (counts and percentages) from all nine hospices aggregated together. The range of aggregated results (minimum and maximum) of the benchmark hospices are also reported, showing the result for the lowest average benchmark hospice and the result for the highest average benchmark hospice for each question. The average results displayed in these tables are then reported visually in a bar-chart for each question.

The benchmark results for daycare are similar to the previous survey in 2006/07; therefore any notable differences (of +/-5% or more) are reported in the written commentary. However different groups of hospices reaching the benchmark in both surveys make it difficult to interpret how meaningful such comparisons of similarities or differences are. Nine hospices achieved the daycare benchmark this year compared to ten in the last survey. Only five out of the nine hospices in this years benchmark results also achieved the daycare benchmark in the 2006/07 survey.

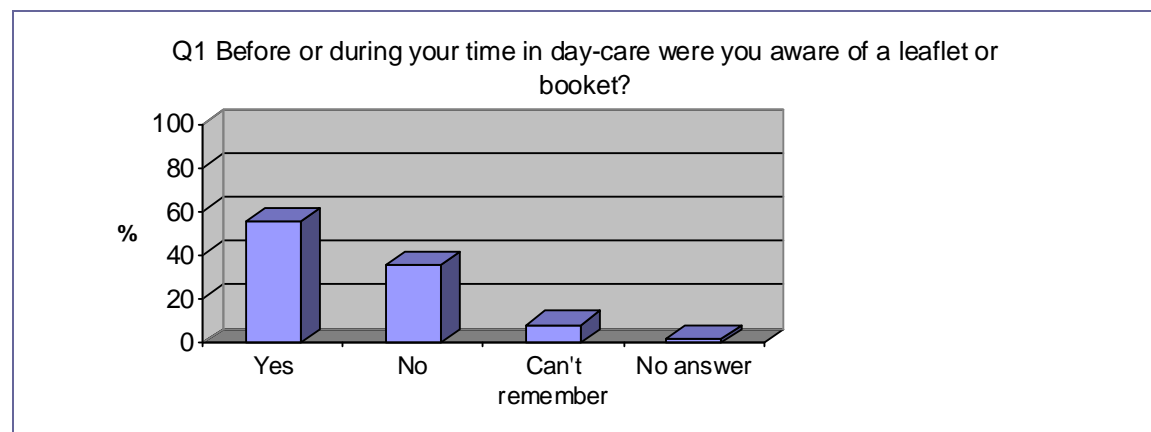
Provision of Information about Daycare Services

All daycare patients were asked whether they were aware of an information leaflet or booklet on the services that their hospice provides. If a patient had looked at the leaflet, they were asked some follow up questions about whether they found the leaflet helpful, easy to understand, whether they found anything to be incorrect, and whether they had any suggestions to make on any other information that should be included in the leaflet.

Just over half of daycare patients (55%) said they were aware of an information leaflet or booklet, which is 12% less than the last survey. There was great variation in awareness of such a leaflet or booklet in some of the benchmark hospices compared to others, e.g. just over two thirds of respondents indicated that they were not aware of such a leaflet or booklet in one of the hospices, whereas in another the vast majority were aware of it. This may indicate the different usage of booklets and leaflets as an information tool within the benchmark hospices. Of the respondents who were aware only two respondents said they didn't actually look at the leaflet or booklet (however a slightly higher percentage didn't answer the subsequent questions on this and so it is possible that these respondents hadn't looked at the leaflet or booklet either).

Q1 Before or during your time in daycare were you aware of a leaflet or booklet?

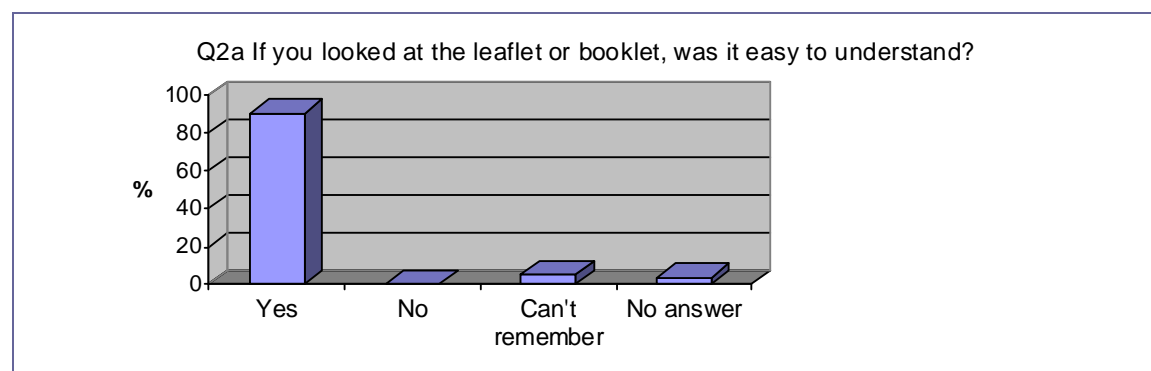
	N	Average (%)	Range (%)
Yes	241	55.3	15.6 – 84.0
No	154	35.3	12.0 – 68.9
Can't remember	34	7.8	0.0 – 15.6
No answer	7	1.6	0.0 – 3.9
Total	436	100	



Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on daycare services, with the vast majority of patients who had looked at the leaflet reporting that it was easy to understand (91%) and that it included information that was helpful to them (89%) which was very similar to previous surveys. No patients said that they felt it was hard to understand or thought it was unhelpful. 8% couldn't remember if the leaflet or booklet was helpful or not.

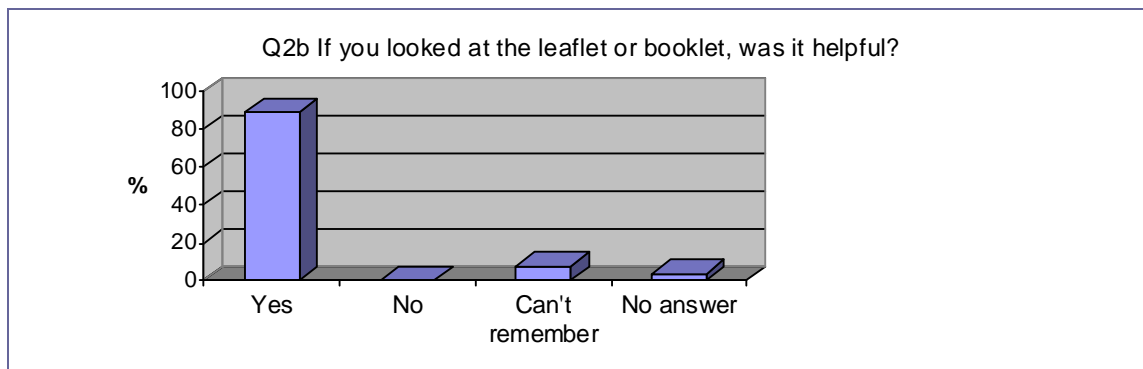
Q2a If you looked at the leaflet or booklet, was it easy to understand?

	N	Average (%)	Range (%)
Yes	225	90.7	75.9 – 100.0
No	0	0.0	0.0 – 0.0
Can't remember	13	5.2	0.0 – 13.8
No answer	10	4.0	0.0 – 12.5
Total	248	100	
Did not look at the leaflet or booklet: 2			
Not applicable: 186			



Q2b If you looked at the leaflet or booklet, was it helpful?

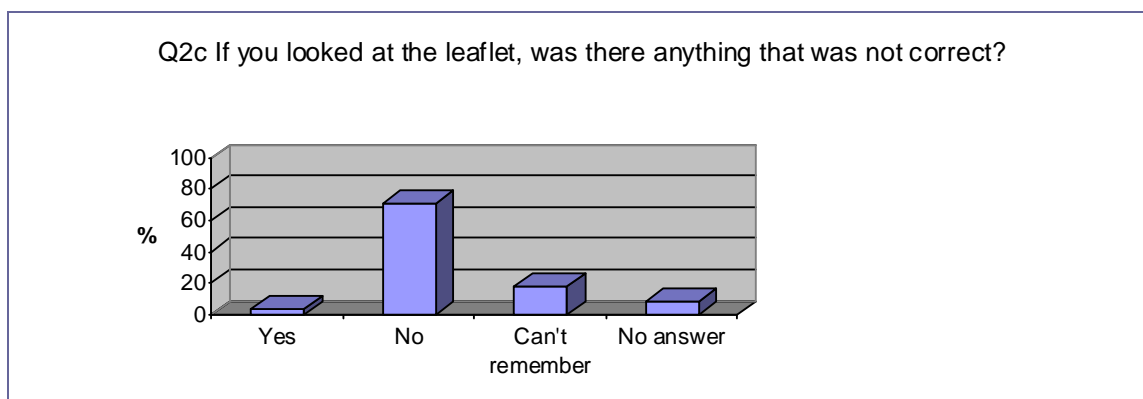
	N	Average (%)	Range (%)
Yes	220	88.7	75.9 – 94.7
No	0	0.0	0.0 - 0.0
Can't remember	19	7.7	3.2 – 17.2
No answer	9	3.6	0.0 – 7.1
Total	248	100	
Did not look at the leaflet or booklet: 2			
Not applicable: 186			



Only 3%, equating to 8 patients, said that they found something to be incorrect in the leaflet or booklet. However 18% said they couldn't remember if they found anything that was incorrect. Only 8% of patients who had looked at the leaflet had made a suggestion of others things that could be included in the leaflet (for comments on incorrect information and suggestions of more information to include in the leaflet see the 4.4 textual comments section of this report).

Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

	N	Average (%)	Range (%)
Yes	8	3.2	0.0 – 12.5
No	175	70.6	57.1 – 90.5
Can't remember	45	18.1	0.0 – 32.4
No answer	20	8.1	0.0 – 28.6
Total	248	100	
Did not look at the leaflet or booklet: 2			
Not applicable: 186			

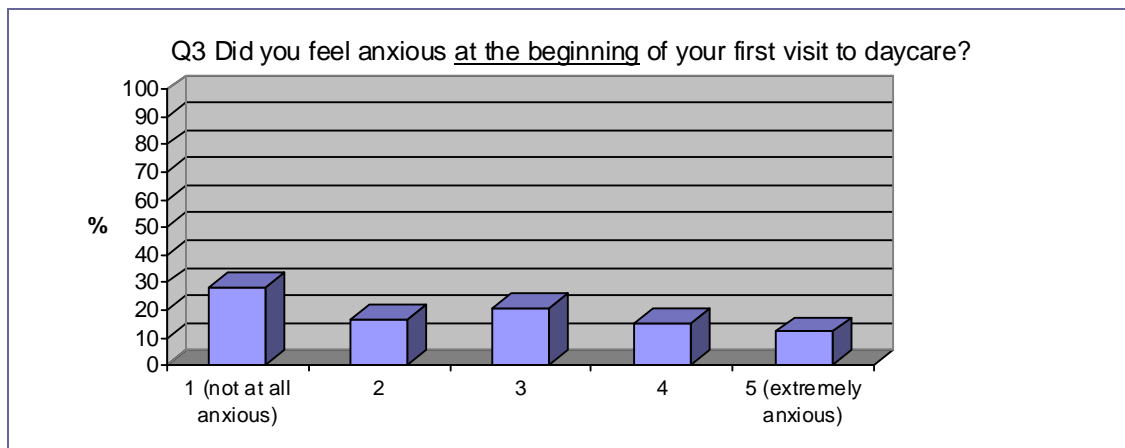


Anxiety on First Daycare Visit

Respondents were asked about how anxious they felt on their first visit to their daycare hospice. The questions asked were designed to measure the difference in anxiety felt at the beginning of their first visit compared to the anxiety they felt at the end of their first visit. The results show that levels of anxiety at the beginning of the first visit were generally low, with 28% of respondents reporting that they were not at all anxious. Answers for 21% of the respondents indicated that they felt neither 'anxious' nor 'not anxious', and 12% felt extremely anxious. Respondents were much less anxious at the end of their first visit, with 65% reporting that they were not anxious at all and only 5% reporting that they felt extremely anxious.

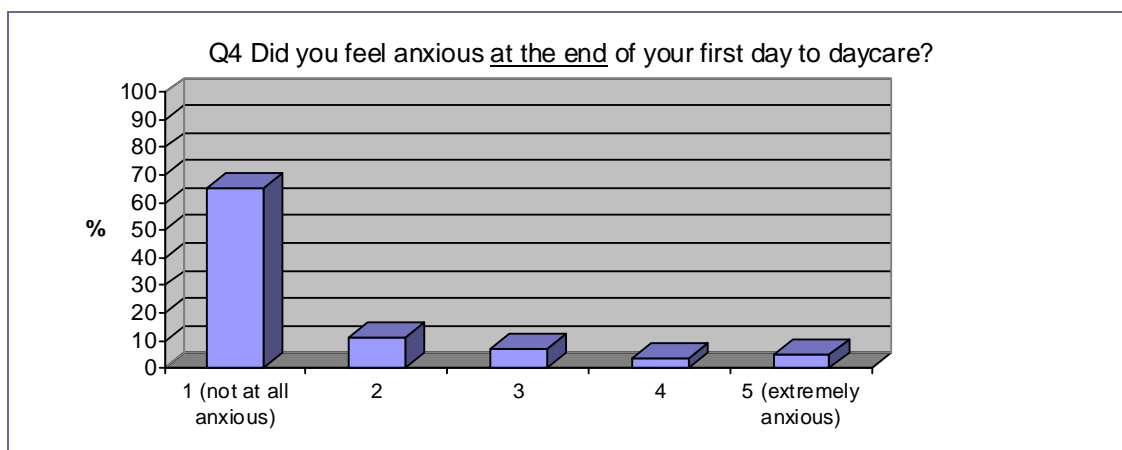
Q3 Did you feel anxious at the beginning of your first visit to daycare?

	N	Average (%)	Range (%)
1. Not at all anxious	124	28.4	23.3 – 42.2
2.	72	16.5	9.1 – 30.0
3.	91	20.9	14.0 – 31.7
4.	67	15.4	9.8 – 25.0
5. Extremely anxious	53	12.2	2.2 – 19.6
Can't remember	9	2.1	0.0 – 5.9
No answer	20	4.6	0.0 – 9.8
Total	436	100	



Q4 Did you feel anxious at the end of your first visit to Day care?

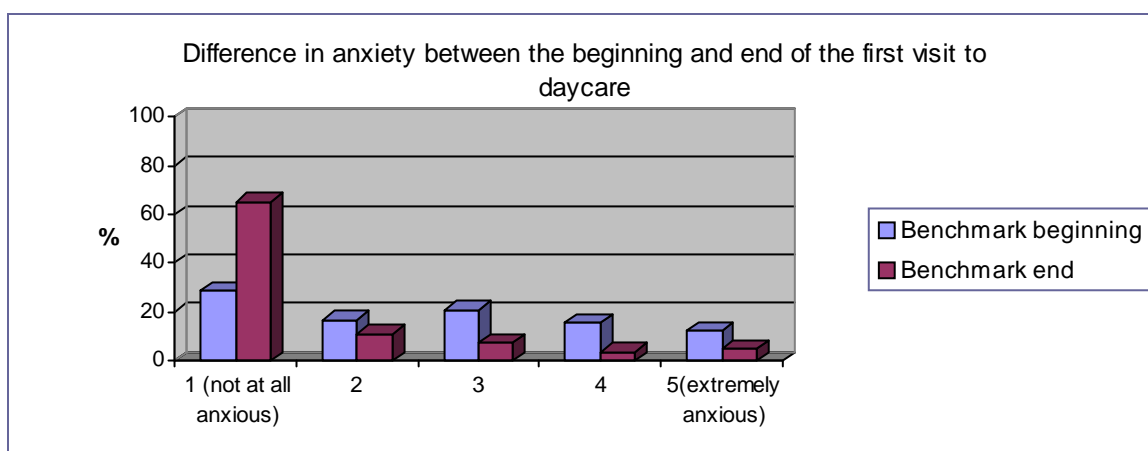
	N	Average (%)	Range (%)
1. Not at all anxious	284	65.1	45.1 – 84.4
2.	48	11.0	4.4 – 18.2
3.	32	7.3	3.9 – 13.7
4.	16	3.7	0.0 – 7.8
5. Extremely anxious	21	4.8	0.0 – 22.7
Can't remember	6	1.4	0.0 – 3.9
No answer	29	6.7	2.3 – 13.7
Total	436	100	



Looking more closely at the change in anxiety from the beginning and end of the first visit, the majority of respondents (60%) were less anxious at the end of the visit compared to the beginning (this is a 5% decrease on the number of patients feeling less anxious compared to the 2006/07 survey). There was only a small change of 4% towards feeling more anxious at the end of the visit compared to the beginning. There was no change in anxiety for 36% of respondents, and these were largely the group who would have felt 'not at all anxious' at the beginning of the visit. Results on change in anxiety were not available for 43 respondents (10%) as they did not answer both of the questions on anxiety before and after their first visit to daycare. This indicates that a higher proportion of respondents chose not to answer these questions compared to the previous survey. Respondents were asked to write down if their hospice could have done anything to help relieve their anxiety on their first visit. 26% of respondents gave an answer and these comments are presented in the 4.4 textual comments section of this report.

Change in anxiety between the beginning and end of the first visit to Daycare (Q3/4)

	N	Average (%)	Range (%)
Less anxious	234	59.5	42.9 – 71.7
No change	142	36.1	23.9 – 52.5
More anxious	17	4.3	0.0 – 23.8
Total	393	100	
Not applicable: 43			

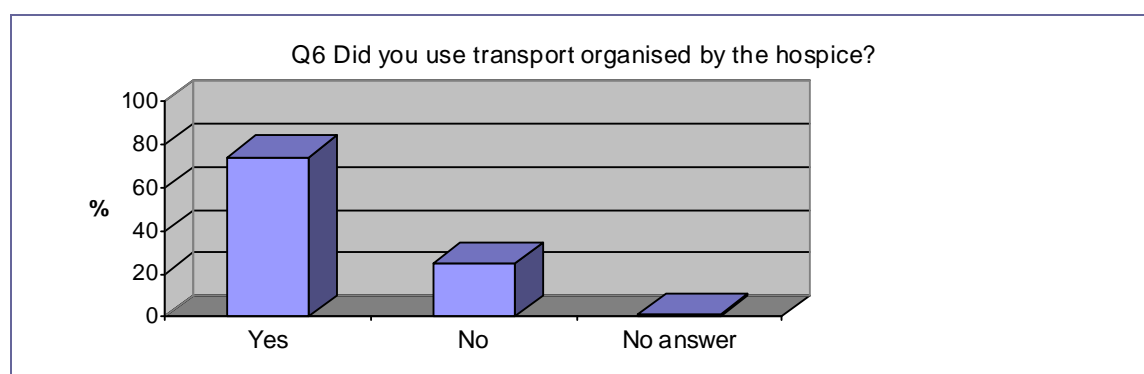


Use of Transport by Daycare Patients

Three quarters of daycare patients (74%), reported that they used transport organised by the hospice (ranging between 59% - 98% for the individual benchmark hospices). As in the previous survey the majority who reported using transport organised by their hospice also reported the standard of this service to be excellent. 76% of those who had used the transport felt the promptness of pick up (i.e. whether they were picked up on time) was excellent compared to 2% who felt it was poor. 72% felt the comfort of the journey was excellent compared to 2% who felt it was poor, and 82% felt the safety aspects were excellent compared to 1% who felt it was poor. The ranges reported below show that there was some variation in the views on hospice transport (more so than the previous survey) but the majority felt the service provided was excellent and few felt it was poor. Further comments made by respondents on hospice transport can be found in the 4.4 textual comments section of this report.

Q6 Did you use transport organised by the hospice?

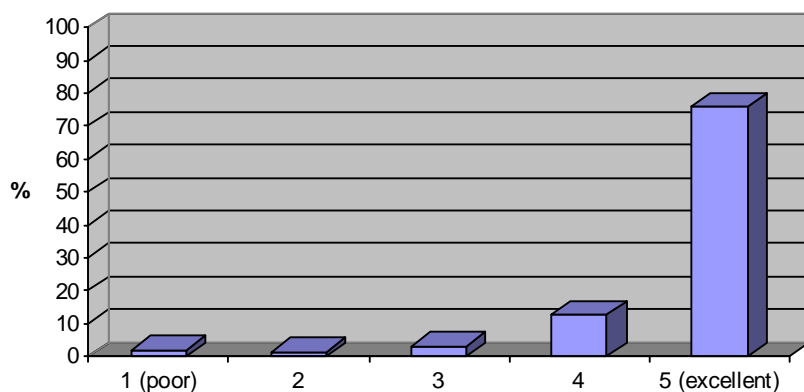
	N	Average (%)	Range (%)
Yes	324	74.3	58.8 – 98.0
No	108	24.8	2.0 – 41.2
No answer	4	0.9	0.0 – 3.3
Total	436	100	



Q7a If you used hospice transport, please circle the score you would give: whether you were picked up on time.

	N	Average (%)	Range (%)
1. Poor	6	1.8	0.0 – 6.7
2.	5	1.5	0.0 – 6.7
3.	10	3.0	0.0 – 5.0
4.	41	12.5	2.6 – 23.3
5. Excellent	249	75.9	53.3 – 93.1
No answer	17	5.2	0.0 – 18.2
Total	328	100	
Not applicable: 108			

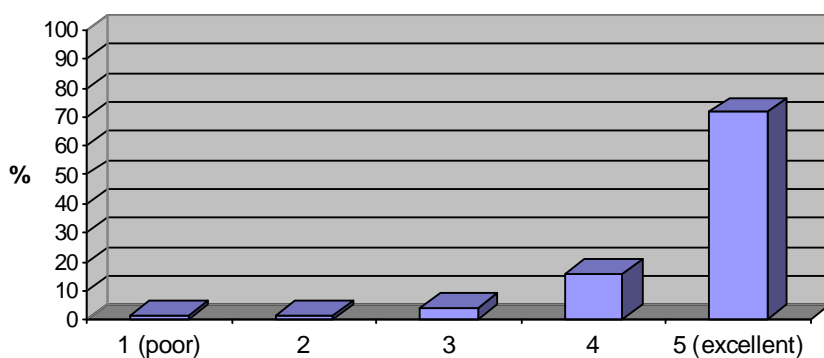
Q7a If you used hospice transport, please circle the score you would give:
whether you were picked up on time.



Q7b If you used hospice transport, please circle the score you would give: comfort of the journey

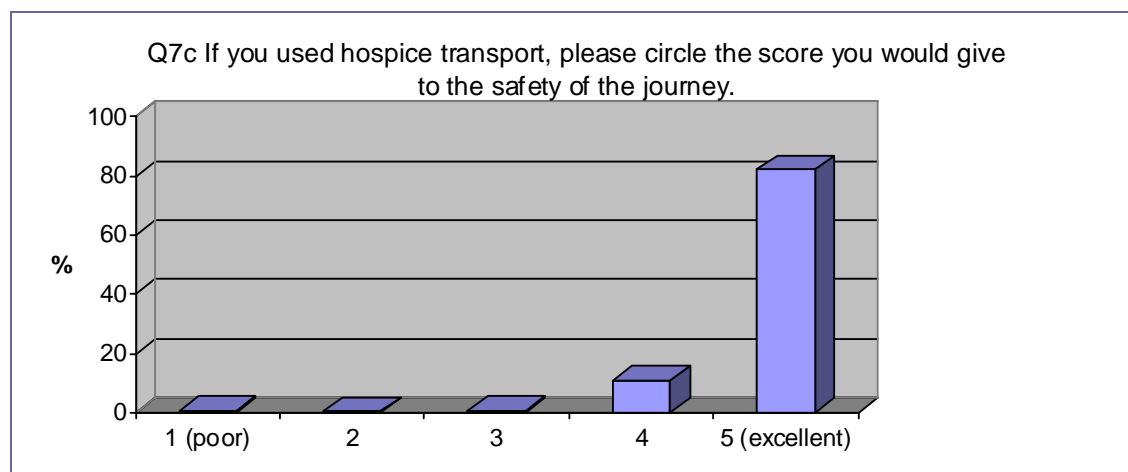
	N	Average (%)	Range (%)
1. Poor	5	1.5	0.0 – 7.4
2.	5	1.5	0.0 – 6.1
3.	14	4.3	0.0 – 10.3
4.	51	15.5	5.1 – 30.0
5. Excellent	235	71.6	46.7 – 87.2
No answer	18	5.5	0.0 – 18.2
Total	328	100	
Not applicable: 108			

Q7b If you used hospice transport, please circle the score you would give:
comfort of the journey.



Q7c If you used hospice transport, please circle the score you would give: safety of the journey

	N	Average (%)	Range (%)
1. Poor	3	0.9	0.0 – 3.7
2.	1	0.3	0.0 – 2.0
3.	2	0.6	0.0 – 3.3
4.	35	10.7	2.6 – 22.2
5. Excellent	269	82.0	66.7 – 95.0
No answer	18	5.5	0.0 – 18.2
Total	328	100	
Not applicable: 108			



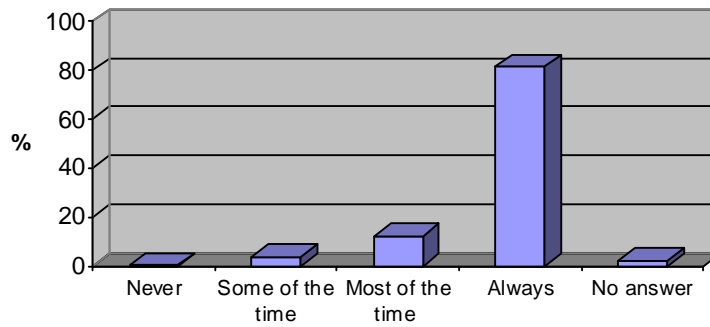
Daycare Staff: Communication and Care

The survey asked patients about the communication and care they had received from staff in daycare. 81% of respondents reported that staff involved in their care always introduced themselves when meeting for the first time. A further 12% said they introduced themselves most of the time and one respondent said that staff had never introduced themselves. As well as an introduction, staff are also regularly explaining what they were doing when caring for patients. 73% reported that staff always explained what they were doing, 21% reported most of the time, and 4 respondents (1%) reported that staff had never explained what they were doing. Patients using daycare services were also asked whether they had confidence in the staff who were caring for them overall. The response to this question was very positive with 91% reporting that they always had confidence in the staff caring for them. One respondent felt that they 'never' had confidence in the staff. Respondents were invited to make further comments on their confidence in staff, which can be found in the 4.4 textual comments section of this report. Overall respondents were positive about the communication and care received from staff, however there was some noticeable variation between individual benchmark hospices with some respondents being less positive than others about the staff.

Q8a While you were in daycare, did staff involved in your care introduce themselves?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.4
Some of the time	17	3.9	0.0 – 12.2
Most of the time	53	12.2	4.9 – 17.6
Always	355	81.4	62.7 – 93.2
No answer	10	2.3	0.0 – 7.8
Total	436	100	

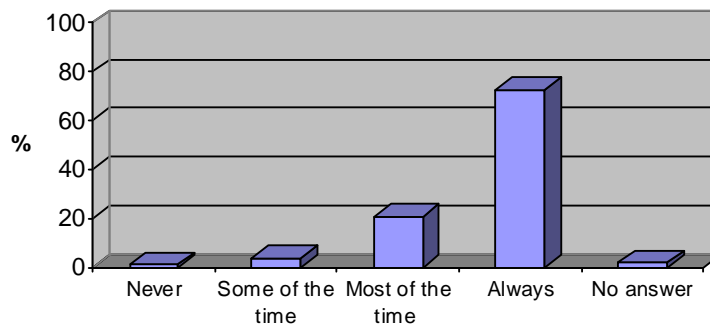
Q8a While you were in daycare, did staff involved in your care introduce themselves?



Q8b While you were in daycare, did staff explain what they were doing?

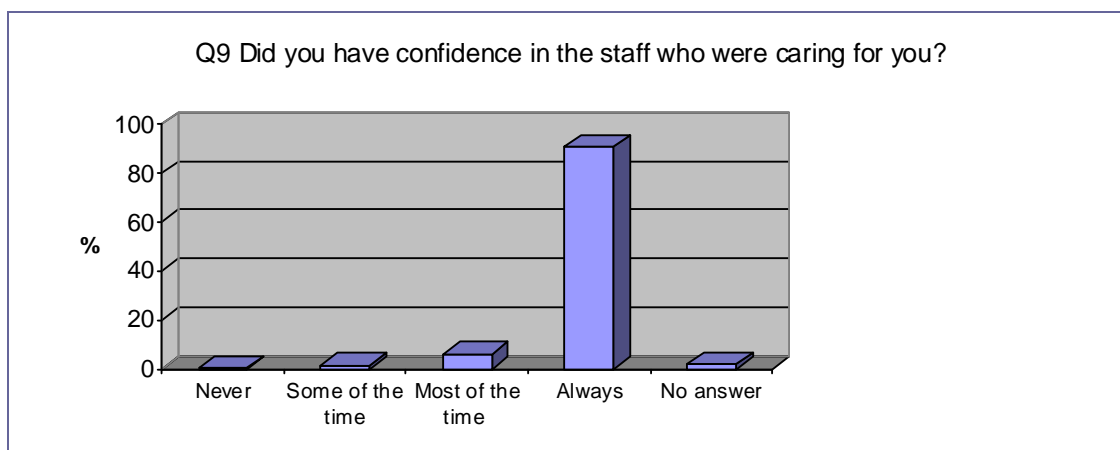
	N	Average (%)	Range (%)
Never	4	0.9	0.0 – 5.9
Some of the time	17	3.9	0.0 – 11.8
Most of the time	90	20.6	6.7 – 29.5
Always	317	72.7	43.1 – 88.9
No answer	8	1.8	0.0 – 5.9
Total	436	100	

Q8b While you were in daycare, did staff explain what they were doing?



Q9 Did you have confidence in the staff who were caring for you?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.0
Some of the time	6	1.4	0.0 – 3.9
Most of the time	26	6.0	2.0 – 17.6
Always	396	90.8	72.5 - 97.7
No answer	7	1.6	0.0 – 4.0
Total	436	100	

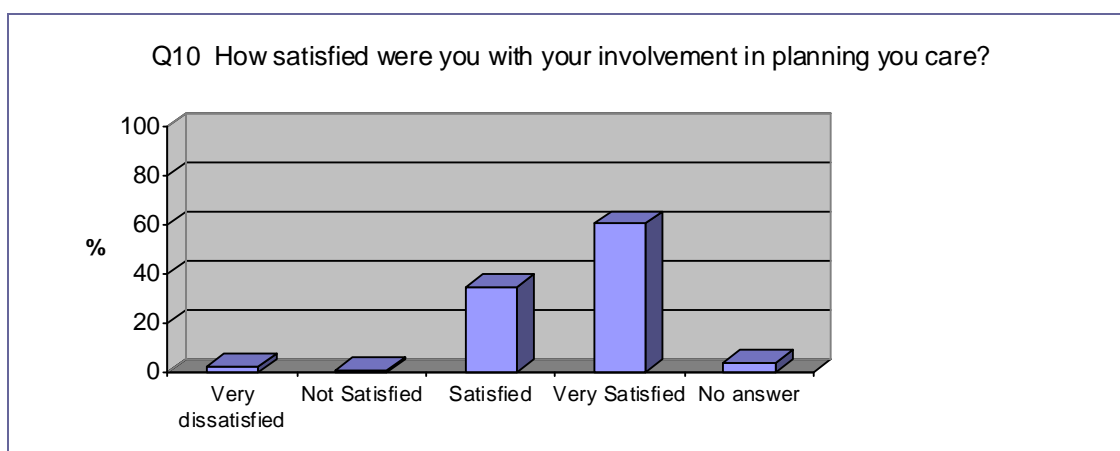


Daycare User Involvement and Understanding

Patients were asked about their overall satisfaction with their involvement in the planning of their care while in daycare. 60% of respondents were very satisfied, which is a 14% decrease compared to the last survey. However a higher percentage (34%) said they were 'satisfied' with the level of involvement in their care (a 12% increase compared to the last survey). Only 2% of respondents were either 'very dissatisfied' or 'not satisfied' with their involvement in their care. Of those who were either dissatisfied or very dissatisfied four respondents made suggestions as to how their hospice could involve them more in the planning of their care (for these suggestions of more information see the 4.4 textual comments sections of this report).

Q10 How satisfied were you with your involvement in planning your care?

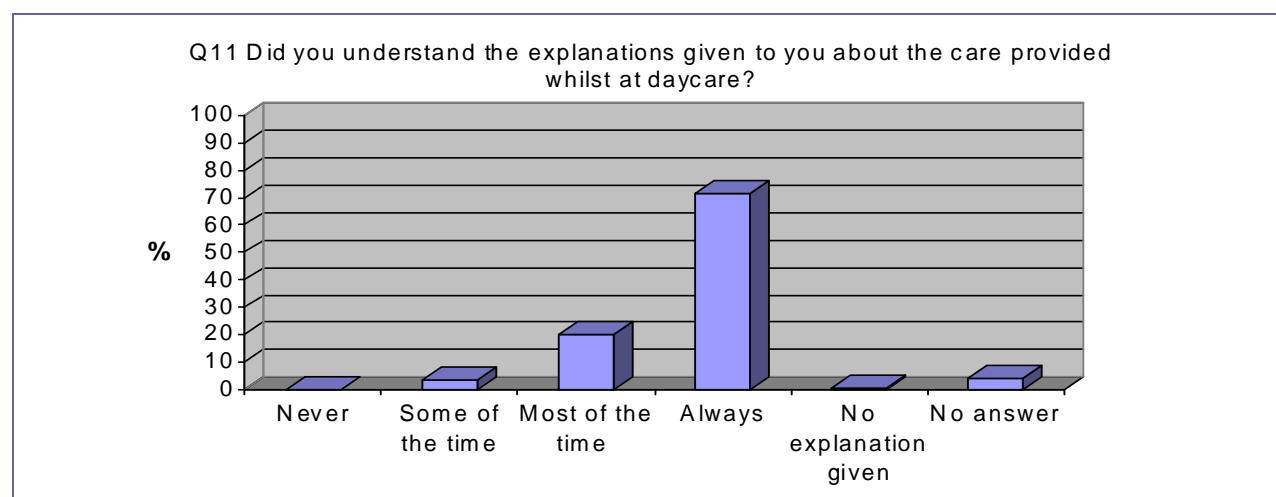
	N	Average (%)	Range (%)
Very dissatisfied	8	1.8	0.0 – 4.9
Not Satisfied	1	0.2	0.0 – 2.0
Satisfied	149	34.2	26.0 – 43.1
Very Satisfied	262	60.1	48.8 – 72.7
No answer	16	3.7	0.0 – 9.8
Total	436	100	



The survey also asked about users understanding of the explanations given to them about their care while in daycare. The majority of respondents felt that they understood the explanations given to them about their care: 72% felt that they always understood the explanations given, and 20% said they understood most of the time. No-one said that they never understood any of the explanations given to them. 10% of respondents gave a response on whether there was any way explanations can be made clearer (which was 5% more compared to the last survey). For these suggestions see the 4.4 textual comments sections of this report.

Q11 Did you understand the explanations given to you about the care provided while you were at daycare (this does not include the care provided by your GP or hospital)?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	16	3.7	0.0 – 6.0
Most of the time	88	20.2	8.3 – 29.4
Always	312	71.6	54.9 – 82.0
No explanation given	2	0.5	0.0 – 2.0
No answer	18	4.1	0.0 – 7.8
Total	436	100	

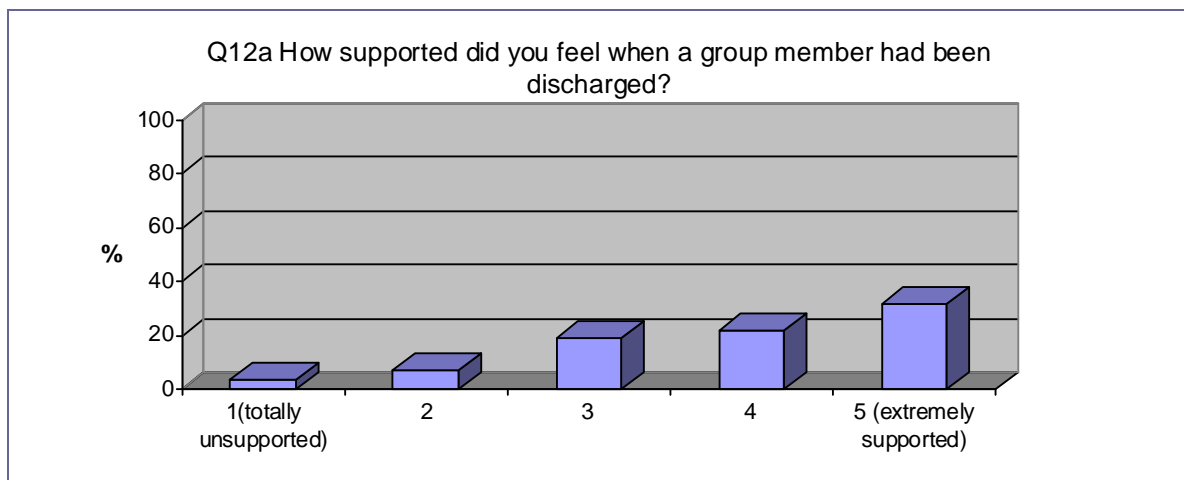


Views of Users on the Support and Courtesy from Daycare Staff

Patients were asked a number of questions in the survey about their views on the support and courtesy from the staff looking after them in daycare. 32% of patients felt extremely supported when a group member had been discharged, with a further 22% feeling supported. The proportion feeling extremely supported had decreased by 9% compared to the previous survey. However it remains a small proportion (4%) that felt totally unsupported. A high proportion of respondents tended not to answer this question (17%) compared to other questions as has been found in previous surveys, 38% of respondents didn't answer this question in one hospice. This may indicate a lower level of certainty of this type of support among patients compared to other areas of care. Also these percentages reflect the fact that almost half the respondents were not aware of anyone being discharged while they were at daycare. In comparison, more respondents felt support was given when a group member had died: 45% said they had felt extremely supported (slightly less than the previous survey), and 4% felt totally unsupported. This question also had a high level of non-completion (15%) in a similar way to the question on support when a patient had been discharged (41% for one benchmark hospice). These two questions had the highest rate of non-completion compared to all other questions in the survey as has been the case in previous surveys.

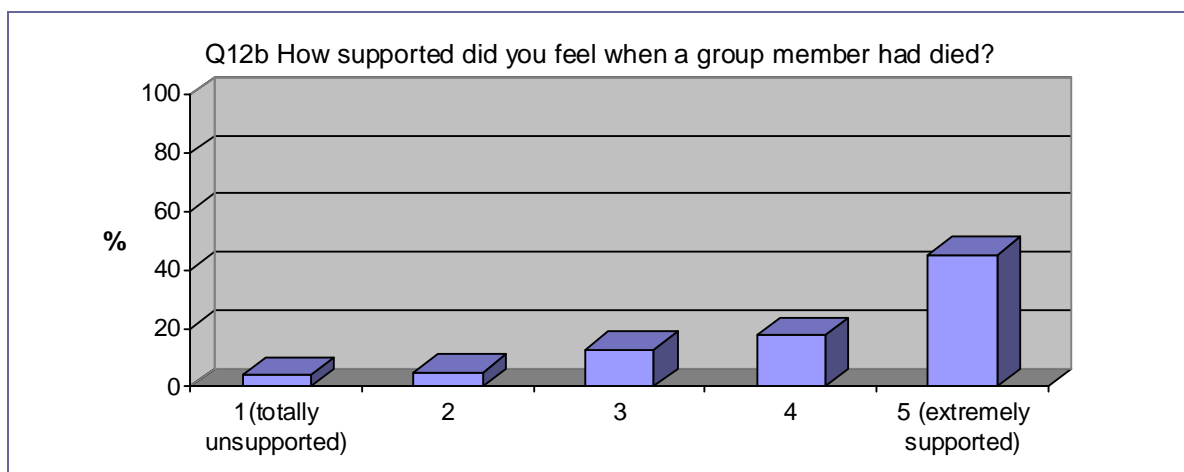
Q12a How supported did you feel when a group member had been discharged?

	N	Average (%)	Range (%)
1. Totally unsupported	9	3.8	0.0 - 11.5
2.	17	7.2	0.0 - 15.4
3.	45	19.1	3.8 - 35.5
4.	51	21.7	7.7 - 42.3
5. Extremely supported	74	31.5	12.8 - 60.0
No answer	39	16.6	0.0 - 37.5
Total	235	100	
Not applicable as no one had been discharged: 201			



Q12b How supported did you feel when a group member had died?

	N	Average (%)	Range (%)
1. Totally unsupported	11	4.2	0.0 - 13.0
2.	13	4.9	0.0 - 20.0
3.	34	12.8	7.1 - 20.6
4.	47	17.7	5.9 - 31.7
5. Extremely supported	120	45.3	28.3 - 71.4
No answer	40	15.1	3.6 - 41.2
Total	265	100	
Not applicable as no one had died: 171			

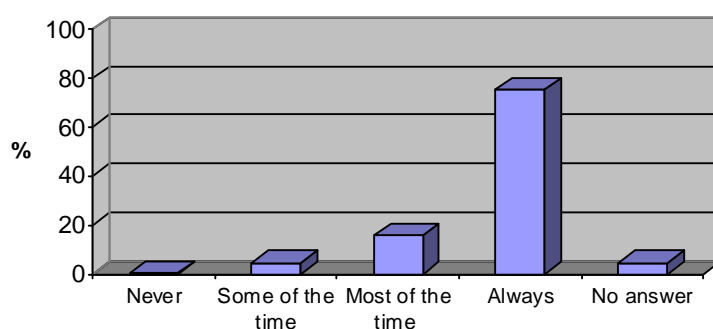


As has been found in previous surveys respondents were more positive in their views on the support they received from staff more generally. 75% of respondents felt that they were always given the opportunity to ask questions when they wanted to, and 16% felt this to be true most of the time. 81% felt that staff always made an effort to meet their individual needs and wishes, and 14% felt this most of the time. Two respondents (1%) felt that staff never made an effort to meet their individual needs and wishes.

Q13 Did you have the opportunity to ask questions when you wanted to?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 1.7
Some of the time	19	4.4	0.0 – 12.2
Most of the time	68	15.6	10.0 – 23.5
Always	328	75.2	66.7 – 86.4
No answer	20	4.6	0.0 – 11.7
Total	436	100	

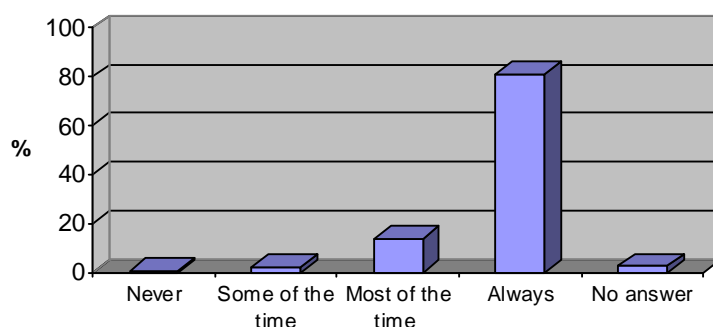
Q13 Did you have the opportunity to ask questions when you wanted to?



Q14 Did you feel staff made an effort to meet your individual needs and wishes?

	N	Average (%)	Range (%)
Never	2	0.5	0.0 – 2.4
Some of the time	9	2.1	0.0 – 5.9
Most of the time	60	13.8	4.0 – 31.4
Always	354	81.2	60.8 – 92.0
No answer	11	2.5	0.0 – 5.9
Total	436	100	

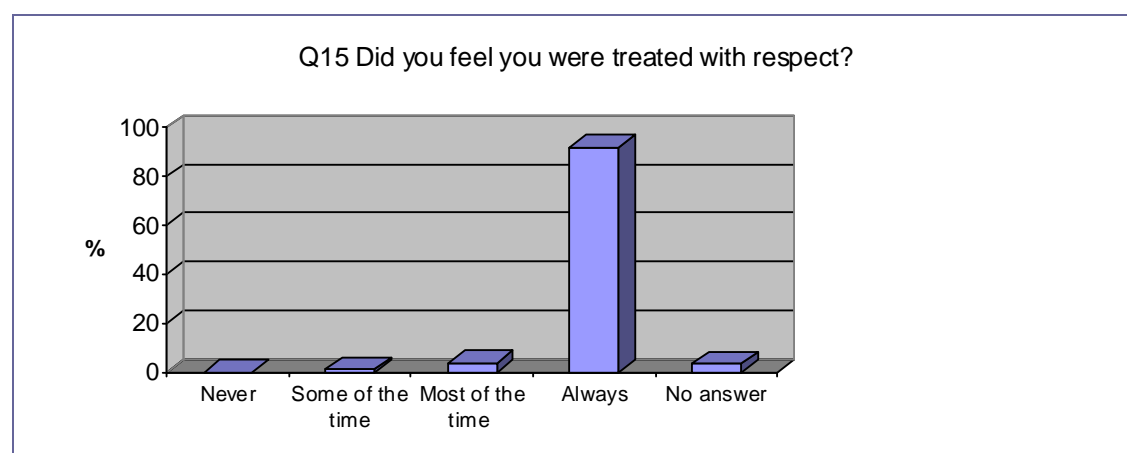
Q14 Did you feel staff made an effort to meet your individual needs and wishes?



The vast majority of patients (92%) felt they were always treated with respect, and 85% felt that their privacy needs were always met when being examined or during discussions with staff for example No-one felt that they were never treated with respect, and one respondent felt that their privacy needs were never met.

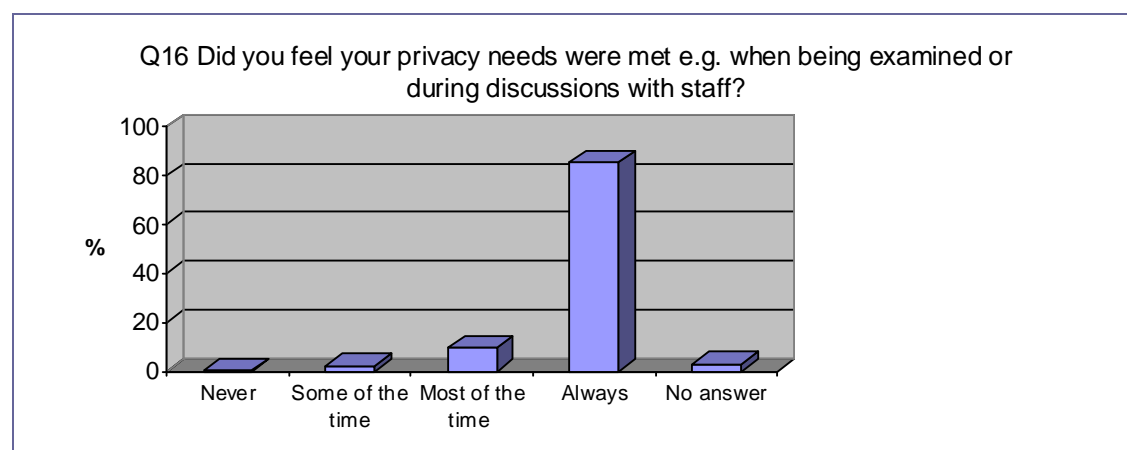
Q15 Did you feel you were treated with respect?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	5	1.1	0.0 - 7.8
Most of the time	17	3.9	0.0 – 8.0
Always	400	91.7	80.4 - 100
No answer	14	3.2	0.0 – 5.9
Total	436	100	



Q16 Did you feel your privacy needs were met, e.g. when being examined or during discussions with staff?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.0
Some of the time	9	2.1	0.0 – 11.8
Most of the time	41	9.4	2.3 – 17.6
Always	372	85.3	70.6 – 97.7
No answer	13	3.0	0.0 – 7.8
Total	436	100	



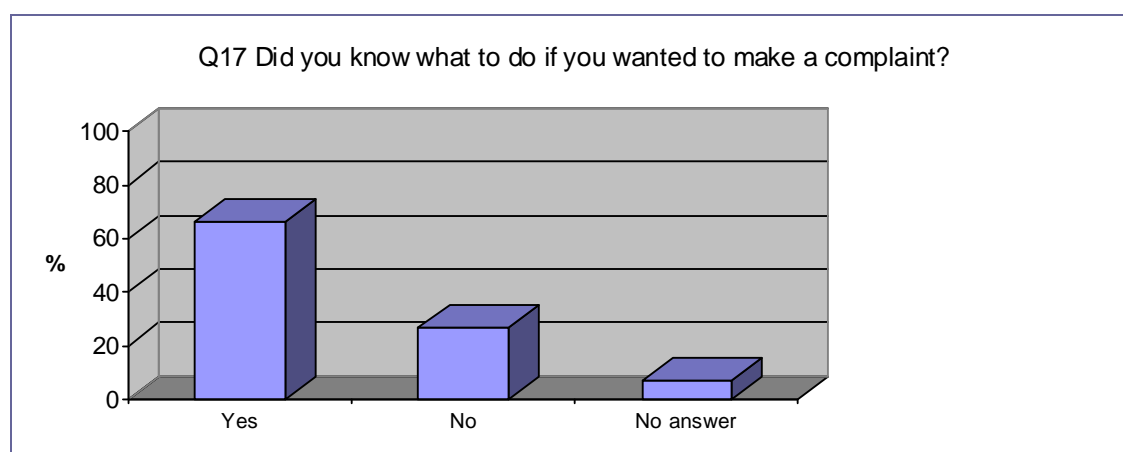
Daycare Facilities and Services

The type of facilities and services offered in daycare can vary greatly. This survey concentrated on general questions about facilities and services which would be applicable to all hospices. It asked about awareness of complaints procedures, what they thought about the quality of the catering, the activities available, the number of staff and volunteers available when needed, and also views on the daycare premise itself, by asking questions about the general environment/surroundings and the cleanliness of the building(s).

Two thirds of respondents (66%) were aware of how to make a complaint compared to 27% who said they did not know what to do if they wanted to make a complaint. Patients were slightly less aware of how to complain in this survey compared to the last survey. Awareness between the benchmark hospices did vary to a lesser degree this time (those aware ranged between 53% - 78%), thus the majority of patients were aware of the procedures in place in all of the benchmark hospices.

Q17 Did you know what to do if you wanted to make a complaint?

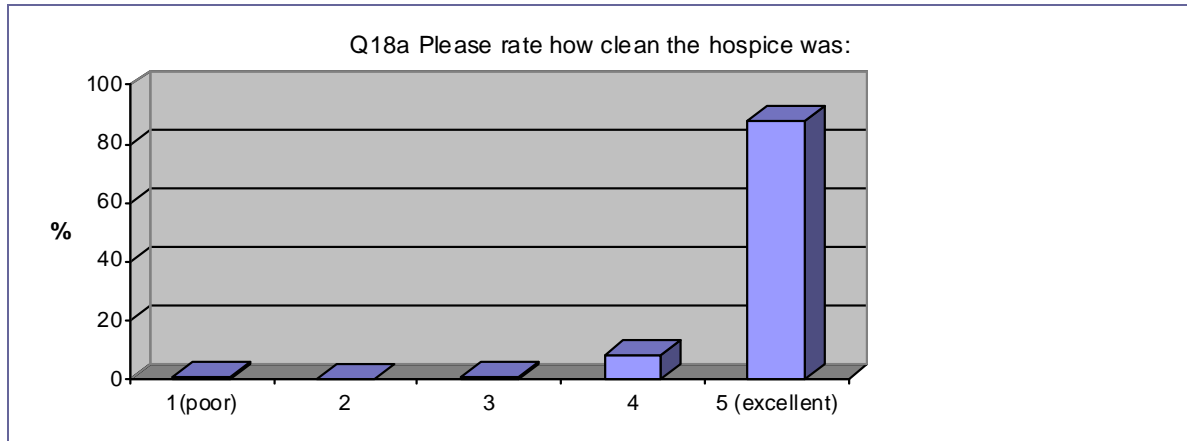
	N	Average (%)	Range (%)
Yes	289	66.3	53.3 – 78.0
No	116	26.6	18.0 – 35.6
No answer	31	7.1	0.0 – 13.7
Total	436	100	



Patients were asked to rate the quality of facilities and services, which were viewed by the majority to be of a high standard and rated as excellent: how clean the hospice was (88%), the quality of the catering (67%), the activities available to take part in (58%) and the general environment and surroundings (81%). Although overall satisfaction was generally high there is a decrease in those giving an excellent rating to the choice of activities available and to the general environment and surroundings (both down by 6% on the previous survey). Only 1% felt that the cleanliness, catering, activities or the environment of their hospice were poor. Although the majority were very happy with them, the quality of the catering and the activities available were the facilities patients were the least impressed with, and there was great variation between the different benchmark hospices. The range of responses for rating the quality of the catering as excellent was between 43%-80%. Likewise, those rating the activities available to take part in as excellent ranged from 46%-76%. However there is less variability between the hospices concerning catering and activities compared to the previous survey. Respondents were invited to make further comments on the facilities and services which can be found in the 4.4 textual comments section of this report. Patients were also asked their view about the number of staff and volunteers working in their hospice. The majority (81%) felt confident that there were always enough staff and volunteers around to offer help if needed, and 16% felt that there were enough most of the time. No one felt there was never enough staff or volunteers available.

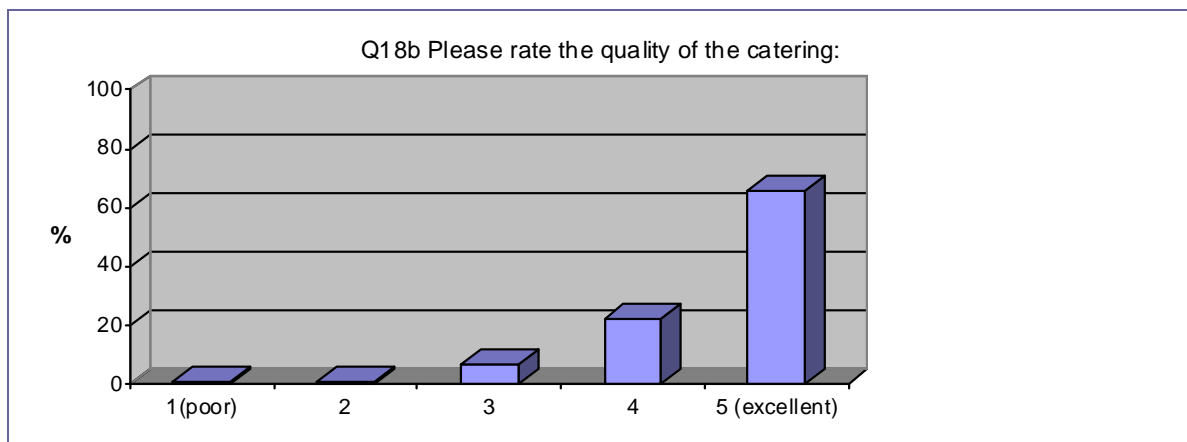
Q18a Please rate how clean the hospice was:

	N	Average (%)	Range (%)
1. Poor	3	0.7	0.0 – 4.0
2.	0	0.0	0.0 – 0.0
3.	3	0.7	0.0 – 3.9
4.	37	8.5	2.0 – 22.0
5. Excellent	382	87.6	72.0 – 97.7
No answer	11	2.5	0.0 – 7.8
Total	436	100	



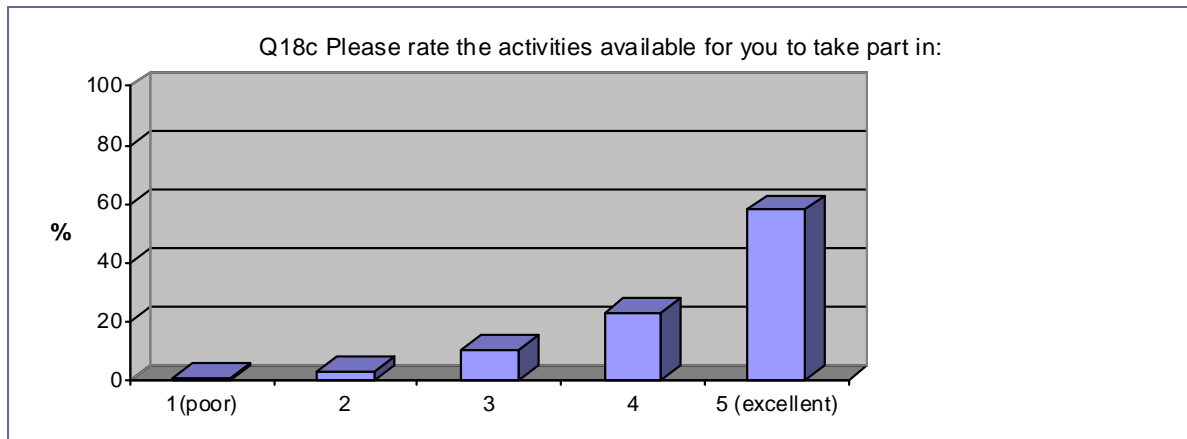
Q18b Please rate the quality of the catering:

	N	Average (%)	Range (%)
1. Poor	3	0.7	0.0 – 3.9
2.	5	1.1	0.0 – 4.0
3.	29	6.7	0.0 – 13.7
4.	96	22.0	11.4 – 35.3
5. Excellent	286	65.6	43.1 – 80.0
No answer	17	3.9	0.0 – 9.8
Total	436	100	



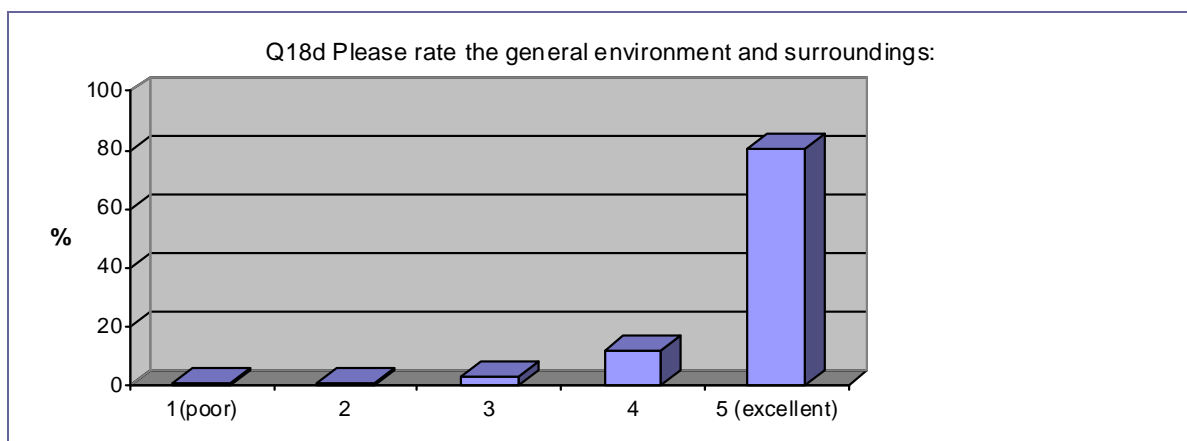
Q18c Please rate the activities available for you to take part in

	N	Average (%)	Range (%)
1. Poor	4	0.9	0.0 – 4.0
2.	14	3.2	0.0 – 5.9
3.	45	10.3	2.0 – 21.6
4.	101	23.2	11.1 – 30.0
5. Excellent	253	58.0	46.3 – 76.0
No answer	19	4.4	0.0 – 12.2
Total	436	100	



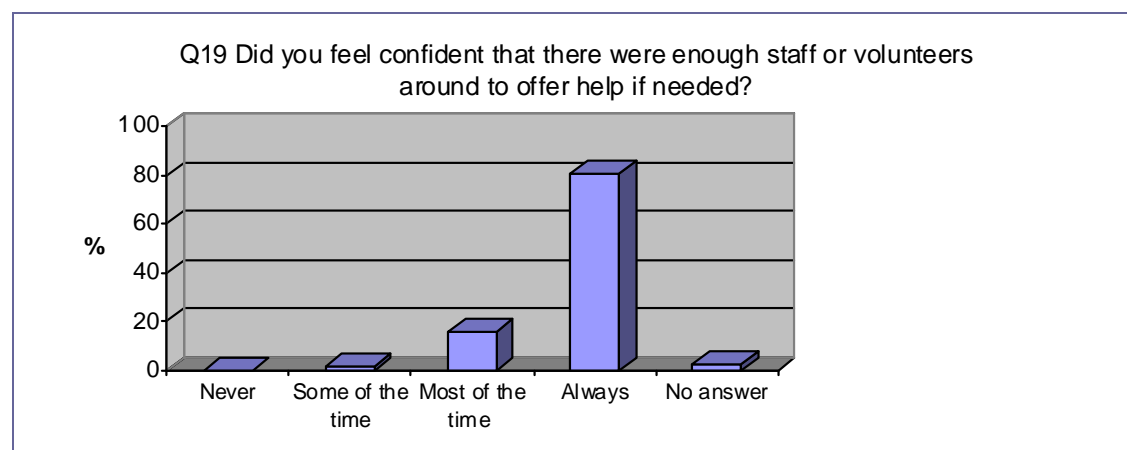
Q18d Please rate the general environment and surroundings:

	N	Average (%)	Range (%)
1. Poor	4	0.9	0.0 – 4.0
2.	3	0.7	0.0 – 3.9
3.	12	2.8	0.0 - 17.6
4.	51	11.7	2.0 – 18.0
5. Excellent	352	80.7	52.6 – 94.0
No answer	14	3.2	0.0 - 7.8
Total	436	100	



Q19 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	7	1.6	0.0 - 4.9
Most of the time	68	15.6	9.1 – 39.2
Always	351	80.5	56.9 – 90.9
No answer	10	2.3	0.0 - 7.8
Total	436	100	



4.3 Average Daycare Results Overall (45 hospices)

The following results report the average responses of all participants aggregated together from 45 hospices who took part in the daycare survey. The total number of completed questionnaires received from daycare patients was 1259, however 15 included comments only and so are excluded from these aggregate results.

Service: Daycare
N: 1244

Q1 Before or during your time in daycare were you aware of an information leaflet or booklet?

Yes	No	Can't remember	No answer
744 (59.8%)	378 (30.4%)	103 (8.3%)	19 (1.5%)

Q2a If you looked at the leaflet or booklet, was it easy to understand?

Yes	No	Can't remember	No answer
698 (92.3%)	1 (0.1%)	26 (3.4%)	31 (4.1%)

Did not look at the leaflet or booklet: 10

Not applicable: 478

Q2b If you looked at the leaflet or booklet, was it helpful?

Yes	No	Can't remember	No answer
690 (91.3%)	2 (0.3%)	35 (4.6%)	29 (3.8%)

Did not look at the leaflet or booklet: 10

Not applicable: 478

Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

Yes	No	Can't remember	No answer
15 (2.0%)	565 (75.2%)	107 (14.2%)	64 (8.5%)

Did not look at the leaflet or booklet: 15

Not applicable: 478

Q3 Did you feel anxious at the beginning of your first visit to daycare?

1 =Not at all anxious → 5 =Extremely anxious					Can't remember	No answer
1	2	3	4	5		
329 (26.4%)	228 (18.3%)	278 (22.3%)	174 (14.0%)	146 (11.7%)	23 (1.8%)	66 (5.3%)

Q4 Did you feel anxious at the end of your first visit to daycare?

1 =Not at all anxious → 5 =Extremely anxious					Can't remember	No answer
1	2	3	4	5		
829 (66.6%)	158 (12.7%)	87 (7.0%)	35 (2.8%)	37 (3.0%)	19 (1.5%)	79 (6.4%)

Change in anxiety between the beginning and end of the first visit to daycare (Q3/4)

Less anxious	No change	More anxious
708 (63.0%)	386 (34.3%)	30 (2.7%)

Not applicable (no answer): 120

Q6 Did you use transport organised by the hospice?

Yes	No	No answer
872 (70.1%)	338 (27.2%)	34 (2.7%)

Q7 If you used transport, please circle the score you would give the following:

	1 =Poor → 5 =Excellent					No answer
	1	2	3	4	5	
Whether you were picked up on time	21 (2.3%)	12 (1.3%)	45 (5.0%)	105 (11.6%)	662 (73.1%)	61 (6.7%)
Comfort of journey	18 (2.0%)	16 (1.8%)	45 (5.0%)	112 (12.4%)	655 (72.3%)	60 (6.6%)
Safety of journey	17 (1.9%)	5 (0.6%)	7 (0.8%)	74 (8.2%)	742 (81.9%)	61 (6.7%)
Not applicable: 338						

Q8a While you were in daycare did staff involved in your care introduce themselves?

Never	Some of the time	Most of the time	Always	No answer
4 (0.3%)	31 (2.5%)	156 (12.5%)	1023 (82.2%)	30 (2.4%)

Q8b While you were in daycare did staff explain what they were doing?

Never	Some of the time	Most of the time	Always	No answer
9 (0.7%)	58 (4.7%)	240 (19.3%)	917 (73.7%)	20 (1.6%)

Q9 Did you have confidence in the staff who were caring for you?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	8 (0.6%)	94 (7.6%)	1124 (90.4%)	17 (1.4%)

Q10 How satisfied were you with your involvement in planning your care?

Very dissatisfied	Not satisfied	Satisfied	Very satisfied	No answer
26 (2.1%)	5 (0.4%)	424 (34.1%)	745 (59.9%)	44 (3.5%)

Q11 Did you understand the explanations given to you about the care provided whilst at daycare (this does not include the care provided by your GP or Hospital)?

Never	Some of the time	Most of the time	Always	No explanation given	No answer
3 (0.2%)	38 (3.1%)	274 (22.0%)	865 (69.5%)	12 (1.0%)	52 (4.2%)

Q12a How supported did you feel when a group member had been discharged?

1 =Totally unsupported → 5=Extremely supported					No answer
1	2	3	4	5	
29 (4.5%)	37 (5.8%)	111 (17.4%)	121 (18.9%)	217 (34.0%)	124 (19.4%)
Not applicable as no one had been discharged: 605					

Q12b How supported did you feel when a group member had died?

1 =Totally unsupported → 5=Extremely supported					No answer
1	2	3	4	5	
34 (4.5%)	32 (4.3%)	104 (13.9%)	145 (19.4%)	333 (44.5%)	101 (13.5%)
Not applicable as no one had died: 495					

Q13 Did you have the opportunity to ask questions when you wanted to?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	41 (3.3%)	220 (17.7%)	936 (75.2%)	45 (3.6%)

Q14 Did you feel staff made an effort to meet your individual needs and wishes?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	18 (1.4%)	179 (14.4%)	1019 (81.9%)	26 (2.1%)

Q15 Did you feel you were treated with respect?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	7 (0.6%)	43 (3.5%)	1167 (93.8%)	27 (2.2%)

Q16 Did you feel your privacy needs were met e.g. when being examined or during discussions with staff?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	14 (1.1%)	98 (7.9%)	1096 (88.1%)	35 (2.8%)

Q17 Did you know what to do if you wanted to make a complaint?

Yes	No	No answer
851 (68.4%)	309 (24.8%)	84 (6.8%)

Q18 Please rate the following by circling your response:

	1 =Poor → 5 =Excellent					No answer
	1	2	3	4	5	
How clean the hospice was	6 (0.5%)	0 (0.0%)	6 (0.5%)	91 (7.3%)	1102 (88.6%)	39 (3.1%)
The quality of the catering	15 (1.2%)	10 (0.8%)	55 (4.4%)	212 (17.0%)	904 (72.7%)	48 (3.9%)
Activities available for you to take part in	15 (1.2%)	29 (2.3%)	122 (9.8%)	293 (23.6%)	726 (58.4%)	59 (4.7%)
The general environment and surroundings	9 (0.7%)	5 (0.4%)	22 (1.8%)	134 (10.8%)	1028 (82.6%)	46 (3.7%)

Q19 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	11 (0.9%)	186 (15.0%)	1002 (80.5%)	45 (3.6%)

4.4 Daycare Textual Comments (45 hospices)

This section summarises the comments from the hospices surveying daycare patients. Each hospice has been supplied with comments made by their patients in their individual hospice daycare results.

In the questionnaire there was room for respondents to write in additional remarks and clarifications. For example, to say in what way patients found information leaflets difficult to understand or unhelpful, or to elaborate on their 'ticked box' answers.

The greatest number of written comments related to the question on confidence in the staff caring for patients (383 comments made) and the open question at the end of the questionnaire which asked for any other general comments and suggestions to help improve daycare services (353 comments). Hospice transport also received a high number of comments (334 comments made). Many patients also made comments about cleanliness, catering, activities and the environment at their hospice (286 comments) and on what could be done to relieve anxiety on the first visit to daycare (263 commented). 2211 comments were made in total by daycare patients.

While the responses were expected to identify areas where improvements might be made to the patients' experience, an over-whelming proportion of what patients wrote was positive and complimentary about daycare services, showing how appreciative they were about many aspects of the care received. Many felt there was nothing they would change about the services and care provided. Only 13% of the comments were ones that hospices could act upon, and these are the main focus of the description of comments that follows. It should be noted that many of these are made by one or two people only.

Information leaflets and booklets (Q2)

Few comments were made about the leaflet or booklet being difficult to understand or unhelpful. Most of the respondents who answered used this space to say that they hadn't been given the information leaflet or had never seen it in their hospice. One respondent said they had been given an information leaflet via the hospital before coming to the hospice but this was out of date. Another respondent felt that the leaflet didn't include enough information, and another felt some of the information in it was misleading because it gave the impression that services available to residents would also be available to day visitors. Some reiterated their answer to the previous question by saying they thought the leaflet was helpful and informative.

Suggestions for other information to include in the leaflet was a description of a typical day at the day hospice so new clients can have more information on what to expect when they come to daycare, and for others have a greater understanding of what hospices offer. Clearer descriptions of certain services such as transport, counselling, options for respite care, and information on the range of activities offered was mentioned:

'The booklet gave the impression of something that they had on but I think it could go deeper as I found out there is a 101 things that the service provides'

Other information considered useful to include was daycare opening times (and when closed in the holidays), patient timetables, support information for relatives e.g. helpline number, details of associations to help financially, policy statement. Others felt that the look and style of the leaflet rather than its content could be improved e.g. by being less formal to look at and read or include larger pictures.

Relieving anxiety (Q5)

The hospice leaflet itself or an information pack were also viewed as useful in helping to relieve anxiety, particularly if given before the first visit so new patients would know what to expect. The great majority of comments were complimentary indicating that everything was done that could have been to help relieve anxiety.

Many respondents said that everyone at their hospice was very kind, friendly, reassuring and welcoming; they were made to feel at ease which helped to relieve their anxiety. For many it was the 'first day nerves' which were dispelled once they arrived and got to meet everyone.

'No, the anxiety is related to the new environment and new people. The wonderful staff put you at ease very quickly'

'I was mainly worried about whether I would fit in and make myself understood. As it turned out my fears were groundless and everyone was friendly and helpful'

'Nothing, I was so relaxed at the end of my first visit. I was already waiting for the next visit'

As similarly described in the quotes above, reasons commonly given for anxiety before their first visit to daycare were fear of the unknown and feeling anxious meeting new people, and the fear that it would be all about talk of illness and thoughts of it being 'doom and gloom' which they found was dispelled on their first visit. Some patients just felt that introduction of patients to new patients by staff and having the opportunity to talk to people would have been helpful, and having the staff taking a little time talking to them on the first day was beneficial. Similarly another suggestion to help anxiety was a 'buddy' system whereby a new patient was given a 'buddy' (another patient to spend time with) for the first part of the day until they felt less anxious.

'More introductions to other patients, I was introduced generally at the beginning of the day but know no names'

'Introduce me individually by name to all the other day care visitors and say what usually goes on on with activities, food, time of refreshments'

'You sat down and talked to me that relieved my anxiety'

Transport (Q7)

Most of the comments were complimentary for the transport services provided, such as 'cannot fault it', 'excellent service' and 'first class'. And they felt it was a reliable service. There was praise for the drivers in particular, who were described as friendly, helpful, considerate, caring and polite. Some also liked the attitude of the drivers where 'nothing was too much trouble' and some respondents liked the way the driver escorted them from their house to the vehicle and back at the end of the day. Similarly patients gave praise for drivers who helped them to get in and out of vehicles, and made sure they got back in-doors safely. Some also commented that they liked to have the same driver. Some said they were extremely grateful for the service otherwise they wouldn't be able to attend the hospice, and some recognised that the drivers were volunteers and were appreciative.

Respondents' comments were less complimentary about the vehicles themselves. Some preferred to have private cars instead of minibuses, or didn't like the use of taxis, where they felt the drivers needed to be more understanding of patients' condition/needs. Some felt the seats should be wider in the vehicles, that it would be useful to have more grab handles and arm rests, and be more suitable and accessible for wheelchair users. In some cases it was felt the vehicles were old and needed replacing with something more modern, and a few thought more care should be taken over bumps in the road to help with the comfort of the journey.

Many patients said the drivers were punctual, but one respondent commented that they would like to know more specifically about pick up times, another did not like them arriving early, another wanted to be informed if someone different was going to collect them, and another liked it that the driver always rang before pick up to check they were going to daycare.

Care staff (Q9)

The question about confidence in the staff got a high proportion of complimentary remarks, often referring to all staff. Generally patients found care staff to be friendly, helpful, and caring. Other hospice staff were also given praise including volunteers, the chaplain, the cleaner 'who smiles and says hello'. Many respondents praised the care staff and their confidence in them:

'The moment I am picked up at my home until I return I cannot tell you how happy I am for everyone's help'

'I think the carers have been well chosen for the jobs which they do. They are all wonderful'

'The staff are absolutely amazing. They are caring, compassionate and above all loving towards every single patient.. I feel relaxed, confident and secure while I am at day therapy'

'They do a superb job. I cannot praise them enough. I am coping with my life with a regained confidence'

'Through their support your life is made worth living'

A few critical comments were that confidence had changed among some respondents due to changes in staff or to their hospice due to changes for financial reasons or because of social services. One respondent observed that nurses seemed to have more paperwork than they had previously which they felt was limiting their time with patients. One respondent felt that there was an occasional lapse of checking of health and welfare if they were attending regularly for a while, on the other hand another respondent thought that it was the new patients that did not get enough help to settle in their hospice. Some felt it was difficult to remember the names of the staff as there was quite a few of them, or certain members of staff were not easy to identify. A list of names and large enough name badges with first names were suggested. One respondent was surprised that patients didn't have a key worker or carer assigned to them to cover problems at home or at the daycare unit if needed.

Care planning (Q10)

Some patients felt that they were not really involved in the planning of their care and were not aware that they could become involved. The view was mixed in that some felt that they would like to be consulted more so they can have a greater understanding whereas others said they did not want to become more involved as the hospice staff would know what to do. Some commented on wanting to know more about the facilities and activities on offer to them in the hospice and how to access them and become involved.

Explanations about care (Q11)

Regarding explanations about care, quite a few patients commented that they thought the explanations were already clear enough and they could not be made clearer. One respondent said that staff would repeat something if they didn't understand it: *'I find that if I don't understand, staff make a point of explaining until I do understand'*. However others felt that it would be helpful to have explanations repeated later as they are forgetful and they can't always remember, particularly if patients are not so 'with it', explanations will be hard to understand sometimes if they are not in the best of health as one respondent pointed out. Others mentioned it would be useful to have a brief talk one-to-one with staff from time to time and not just at the start of daycare. One respondent felt they didn't understand the language used and another said they need to talk louder in order to hear when giving explanations.

Other suggestions made were to have written information or a leaflet that was more specific, a list or a care plan setting out the therapies offered to help manage pain and symptoms. One respondent said the staff sat them with a lady who had the operation they were expecting which they thought was a good idea. Some respondents felt initially that the role of daycare (and the different roles of staff within it) were not properly explained to them,

e.g. someone didn't know why they were told they had to come once a week, another person wasn't sure if they could ask nursing staff about medical problems. One respondent noted that the standard of explanation wasn't so high in daycare as it had been as an inpatient.

Hospice cleanliness, catering, activities, general environment and surroundings (Q18)

These questions elicited many comments, most of which were complimentary, indicating how much patients valued the service provided and looked forward to their visit, for some it was their 'home from home'. Two patients wrote:

'I am so grateful to the staff, the general environment, the surroundings and consider myself to be truly lucky'

'It is very peaceful and relaxing. It is a day I really look forward to'

Other complimentary comments were that the hospice was *'like a posh hotel'*, and *'The Queen could not be treated better'*. Some respondents were complimentary about the catering and activities on offer (these areas also produced the more critical comments) and there were some comments about aspects of the premises. These included the following:

Catering – Some felt the menu was limited and often predictable, and simply would have liked a greater choice and more variation. Some had problems with the choice of food on the menu due to food sensitivities or their illness preventing them being able to enjoy all the food on offer. One respondent thought that a small contribution could be given for catering.

Activities – Many commented that they would like a greater variety of activities or that they were held more regularly. One respondent said they had a massage session but never got a second appointment when they asked. Some felt that the rest of the time you were sat around in a circle with no activity at all which one respondent mentioned can be *'very depressing at times'*. It was felt by some that more activities were needed to suit younger patients or that more male patients would enjoy e.g. a snooker table. Some felt that the activities were particularly arts and crafts orientated and other options like 'sing along' or 'music' would be preferred. On the other hand others complained of noise from such activities and liked the peaceful quiet atmosphere at the hospice. Access to services like a hairdresser at daycare was also suggested by a few respondents.

Premises – Few respondents commented on the cleanliness of their hospice but those that did praised the cleanliness of the buildings saying *'the cleanliness was faultless'*. The 'beautiful' garden areas were particularly enjoyed and patients liked to walk around them. More critical comments were made about the design of the premises. Some patients mentioned the lack of space or poor layout and facilities in the hospice buildings which impacted on their general experience e.g. kitchen too small, some doors could be more wheelchair accessible, lack of space in general which doesn't promote movement around the hospice, and no loop system for people with a hearing impairment. Some comments were made about the toilet facilities e.g. height of the toilet too low, should have separate facilities for men and women, should include a mirror which is useful for wig adjustment. Building work and recent refurbishment in some hospices was mentioned. Some felt the refurbishment was 'excellent' and others felt the change wasn't for the better e.g. not a good use of space, new chairs are less comfortable, the laminate floor 'echoing'.

Confidence in number of staff available (Q19)

This was a new open response question this year and like other questions about the staff very complimentary responses were mostly given such as *'all services were beyond expectation'* and *'staff and volunteers were always there for you'*. The time and dedication of staff and volunteers was appreciated; they *'are to be commended for their efforts'* and there was *'admiration for those who give up so much time'*. Many respondents commented that there were enough staff available with comments like *'help was always at hand'*. In some cases

it was mentioned that staff would be busy or short staffed, the holidays periods were noted as a period when this would happen. Some said that despite being short staffed *'all the staff and volunteers would find time to help', and 'they worked hard to spread themselves around'*. One respondent said *'when short of staff, the volunteers seem to pull extra out of the bag'*. There were mixed views regarding volunteers: some felt there were not enough volunteers available, one felt there were too many, another felt the volunteers did excellent work but there is not enough back up from the permanent staff. Others felt that the staff and volunteers worked well together as a team.

Overall comments (Q20)

Many comments were written, most of which were again very positive about the care received, and reiterated what had been said in the answers to earlier questions. Some commented that they couldn't see how the service could be improved, saying *'how can you improve perfection?'* and *'you cannot better the best'*. One respondent said the *'challenge is to maintain service at present high standard'* and another said that their hospice *'is the best medication I take'*.

Patients continued to make remarks about activities, staff and the excellent service. Specific suggestions however were made about having more frequent activities, treatments, outings and better transport. Many said they enjoyed their weekly visit and it would be sad to have to leave. A few wished they were able to attend daycare more frequently or for longer. Some took the opportunity to say that the hospice should increase its advertising or have an open day to show more widely to the public the good work and care giving they do and help potential users to not be intimidated about using day hospices.

The Questionnaire (Q21)

The majority of comments made about the questionnaire were positive, saying it was fair, clear, easy to follow and to complete. Some found it to be comprehensive, covering all aspects of their care: *'the questions are well balanced and cover all aspects of the function of the hospices'*. There were other topic areas some thought should be included, one respondent thought it could ask more about the nursing care and attention from doctors, another thought it could ask about the emotional needs of patients, some just wanted more space to write their open text answers.

There were a few more critical comments regarding the content and style of the questionnaire. A few felt the questionnaire was too long, one respondent in each case said the questionnaire *'jumps about a bit'* between topics, the rating scales should be consistent, some of the questions were vague. Others said they didn't understand some of the questions but didn't tend to say which questions these were. Of those that did q12 and q18 caused some confusion. Some were not sure if certain questions always applied to them, e.g. if they were a respite patient or just attending on a drop in basis. People tended to comment positively on the layout but it was noted by a couple of respondents that some questions were split across two pages when the questionnaire was printed. Overall the comments made about the questionnaire were positive, with some suggestions that can be used in future years.

5. Results: Inpatient

This section includes the results of the survey for hospice inpatients.

5.1 Individual Hospice Inpatient Results

Individual hospice results are included in the reports given to each participating hospice.

5.2 Benchmark Inpatient Results (4 hospices)

Four hospices reached the benchmark of a minimum of 40 or more returned inpatient questionnaires and are included in the benchmark results representing 193 patient views. This section of the report gives an overview of the aggregate results of these hospices by presenting the results in tables, charts and a written commentary of the findings for each area covered by the survey. These were provision of information about services, staff communication and care, user involvement and understanding, views of users on support and respect they receive from staff, views on hospice facilities and services and users experience when calling for assistance.

The results, in table form, report the average patient responses (counts and percentages) for all four hospices aggregated together. The range of aggregated results (minimum and maximum) of the four benchmark hospices is also reported, showing the result for the lowest average benchmark hospice and the result for the highest average benchmark hospice for each question. The average results displayed in these tables are then reported visually in a bar-chart for each question. Any notable differences in the results compared to the 2006/07 survey (of +/-5% or more) are reported in the written commentary. Different groups of hospices reaching the benchmark in each survey make it difficult to interpret how meaningful such comparisons of similarities or differences are. Only one of the four hospices in this years benchmark results also achieved the inpatient benchmark in the 2006/07 survey.

The number of hospices reaching the benchmark is low compared to the 2006/07 survey where nine hospices reached the benchmark and only two more hospices participated in the inpatient survey. However it is possible that this was a remarkably high year as the 2004/05 survey achieved similar benchmark number to this year (five) with the same number of hospices participating (46). These figures perhaps demonstrate that the response achievable is very much dependent on the characteristics of the hospices that decide to take part and reflective on the fact that 40 or more responses from patients at discharge can be hard to achieve for many hospice inpatient services. Therefore readers should be mindful of the fact that only four hospices are reported when interpreting these results and any differences in comparison with the last survey, as one hospice that has much lower or higher levels of satisfaction would have a greater impact on the average result.

Provision of Information about Inpatient Services

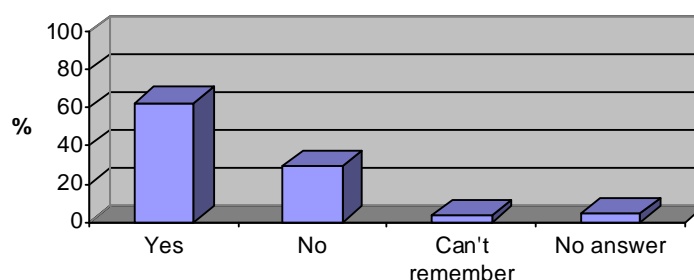
Inpatients were asked whether they were aware of an information leaflet or booklet on the services that their hospice provides. If a patient had looked at the leaflet, they were asked some follow up questions about whether they found the leaflet helpful, easy to understand, whether they found anything to be incorrect, and whether they had any suggestions to make of other information that should be included in the leaflet.

63% of inpatients were aware of their hospices information leaflet or booklet. Awareness of the leaflet varied considerably between benchmark hospices (ranging from: 38% to 88%).

Q1 During your time on the ward, were you aware of a leaflet or booklet?

	N	Average (%)	Range (%)
Yes	121	62.7	38.1 – 88.2
No	57	29.5	7.8 – 52.4
Can't remember	6	3.1	0.0 – 9.1
No answer	9	4.7	2.3 – 7.1
Total	193	100	

Q1 During your time on the ward, were you aware of a leaflet or booklet?

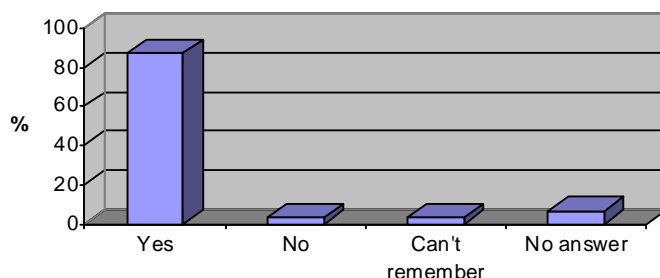


Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on inpatient services, with the majority of patients who had looked at the leaflet reporting that it was easy to understand (87%). 10% either said they couldn't remember or did not answer the question. Only four patients felt that the leaflet wasn't easy to understand, and two commented further on this.

Q2a If you looked at the leaflet or booklet, was it easy to understand?

	N	Average (%)	Range (%)
Yes	108	87.1	73.7 – 95.7
No	4	3.2	0.0 – 11.8
Can't remember	4	3.2	0.0 – 5.9
No answer	8	6.5	0.0 – 26.3
Total	124	100	
Did not look at the leaflet or booklet: 6			
Not applicable: 63			

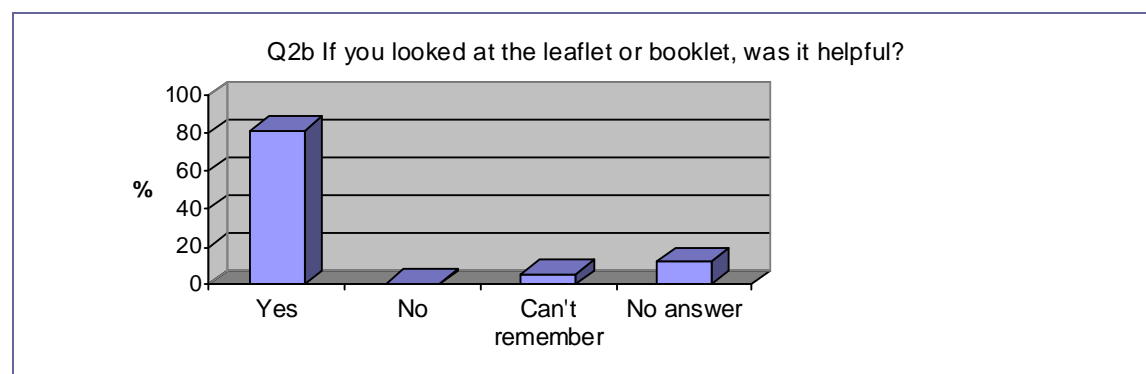
Q2a If you looked at the leaflet or booklet, was it easy to understand?



The majority of patients also felt that the leaflet included information that was helpful to them (81%). This is slightly lower than last year, but a slightly higher proportion (12%) did not answer the question. Only one respondent said they found the leaflet or booklet unhelpful. 7% of patients who had looked at the leaflet said that they found something to be incorrect and a further 7% of patients who had looked at the leaflet had made a suggestion for including further or different information (for suggestions of more information see the 5.4 textual comments section of this report).

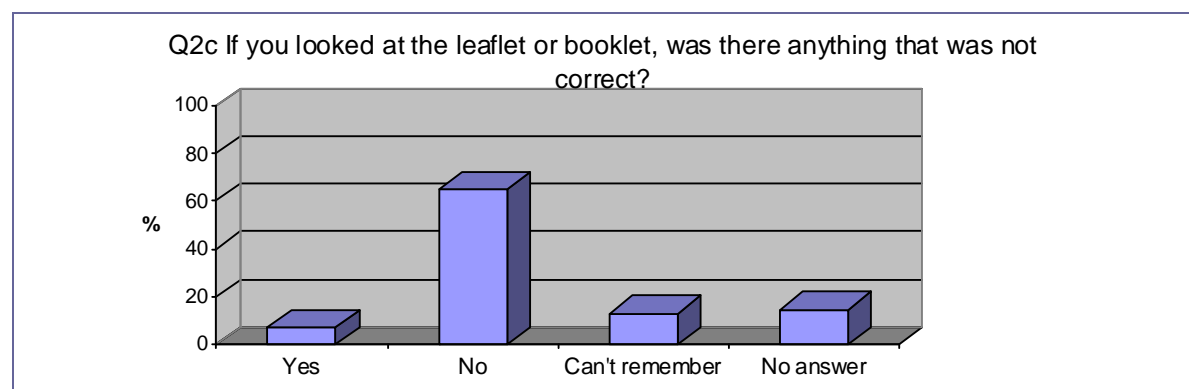
Q2b If you looked at the leaflet or booklet, was it helpful?

	N	Average (%)	Range (%)
Yes	100	81.3	63.2 – 90.2
No	1	0.8	0.0 – 5.9
Can't remember	7	5.7	0.0 – 17.6
No answer	15	12.2	4.9 – 36.8
Total	123	100	
Did not look at the leaflet or booklet: 7			
Not applicable: 63			



Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

	N	Average (%)	Range (%)
Yes	9	7.4	0.0 – 12.5
No	79	64.8	50.0 – 73.3
Can't remember	16	13.1	5.3 – 25.0
No answer	18	14.8	4.4 – 26.3
Total	122	100	
Did not look at the leaflet or booklet: 8			
Not applicable: 63			

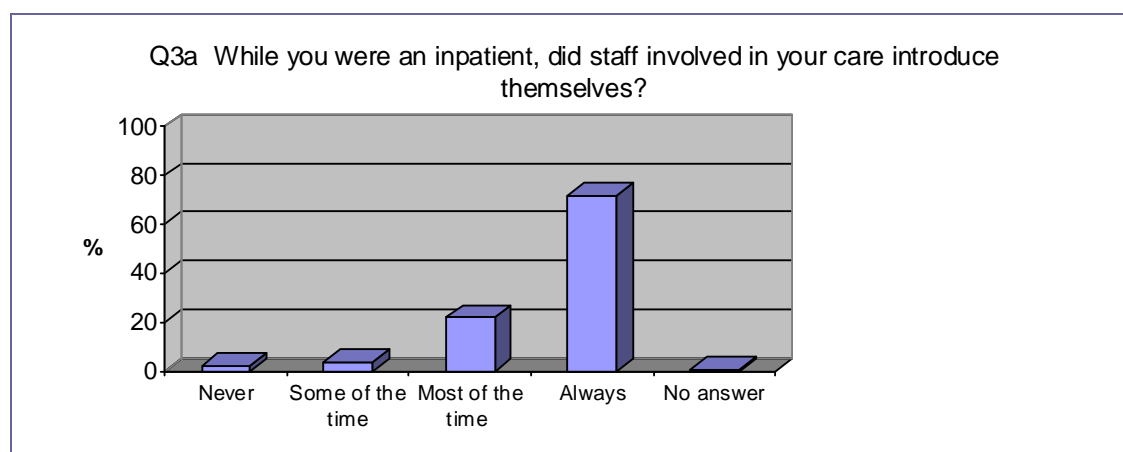


Inpatient Staff Communication and Care

The survey asked inpatients about the communication and care they had received from staff on the ward. The majority (72%) of respondents reported that staff involved in their care always introduced themselves when they first met. A further 22% said they introduced themselves most of the time and four patients (2%) reported that staff had never introduced themselves. Looking at the range of results, the proportion of staff always introducing themselves was slightly more varied between hospices compared to the previous survey (50% to 83%).

Q3a. While you were an inpatient, did staff involved in your care introduce themselves?

	N	Average (%)	Range (%)
Never	4	2.1	0.0 – 9.1
Some of the time	7	3.6	1.8 – 6.8
Most of the time	42	21.8	11.9 – 34.1
Always	139	72.0	50.0 – 83.3
No answer	1	0.5	0.0 – 1.8
Total	193	100	

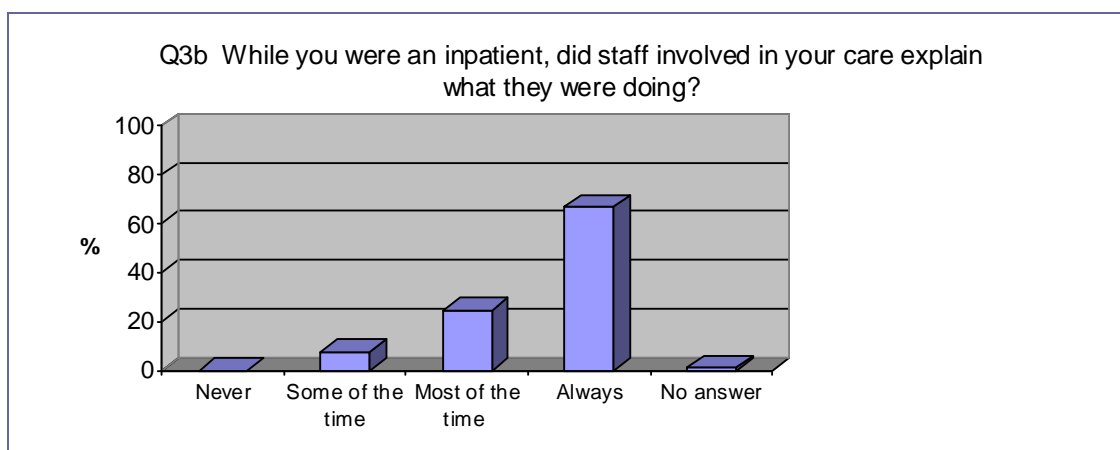


As well as staff introducing themselves, patients were asked if the staff gave explanations for what they were doing when involved in their care. Two thirds (67%) of respondents reported that staff always explained what they were doing, which is a 6% decrease on the previous survey. 24% reported that they explained most of the time, and no patients reported that staff had never explained what they were doing. There was a broader range of responses across the benchmark hospices from patients who always felt staff explained what they were doing in this years survey benchmark compared to the last survey (39% to 80%).

Inpatients were also asked whether they had confidence in the staff that were caring for them. The response was very positive with 85% reporting they always had confidence, and 12% most of the time. There were no patients who felt that they never had confidence in the staff. Respondents were invited to make further comments on their confidence in staff. 29% of respondents commented on this, an overview of all comments can be found in the 5.4 textual comments section of this report.

Q3b. While you were an inpatient, did staff involved in your care explain what they were doing?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	15	7.8	1.8 – 22.7
Most of the time	47	24.4	16.7 – 36.4
Always	129	66.8	38.6 – 80.4
No answer	2	1.0	0.0 – 2.3
Total	193	100	



Q4. Did you have confidence in the staff who were caring for you?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	4	2.1	1.8 – 2.4
Most of the time	24	12.4	9.8 – 22.7
Always	164	85.0	75.0 – 88.2
No answer	1	0.5	0.0 – 1.8
Total	193	100	

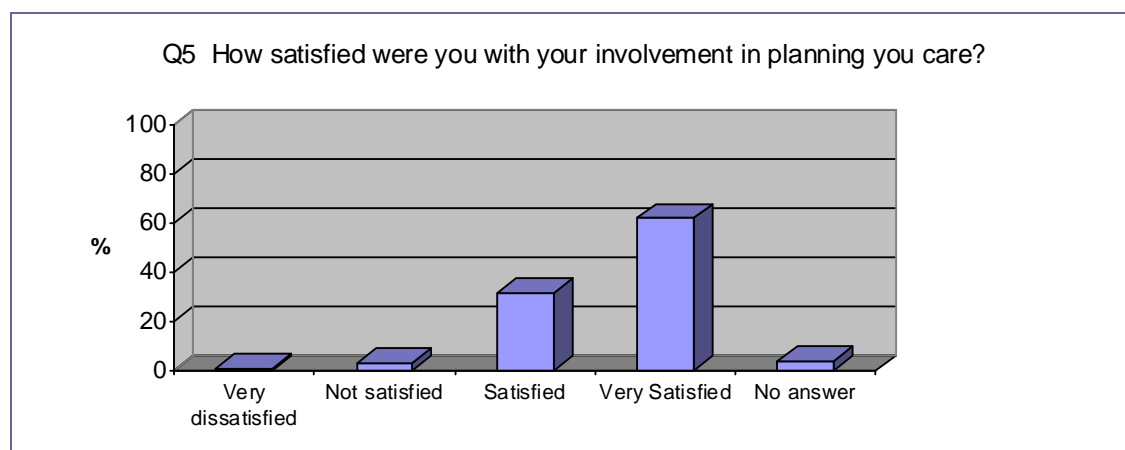


Inpatient Involvement and Understanding

Patients were asked how satisfied they had been with their involvement in the planning of their care while on the ward as an inpatient. 62% of respondents were very satisfied (which is a 6% decrease compared to the last survey). In turn there has been an increase in the proportion saying they were merely 'satisfied' with the level of involvement in their care (31%). Only a small proportion were either 'dissatisfied' or 'very dissatisfied' and 4% didn't answer the question. These respondents were given the opportunity to suggest how they could be involved more in the planning of their care (for these suggestions of more information see the 5.4 textual comments section of this report).

Q5 How satisfied were you with your involvement in planning your care?

	N	Average (%)	Range (%)
Very dissatisfied	1	0.5	0.0 -2.0
Not satisfied	6	3.1	0.0 – 9.1
Satisfied	60	31.1	21.6 – 50.0
Very Satisfied	119	61.7	31.8– 76.8
No answer	7	3.6	0.0 – 9.1
Total	193	100	



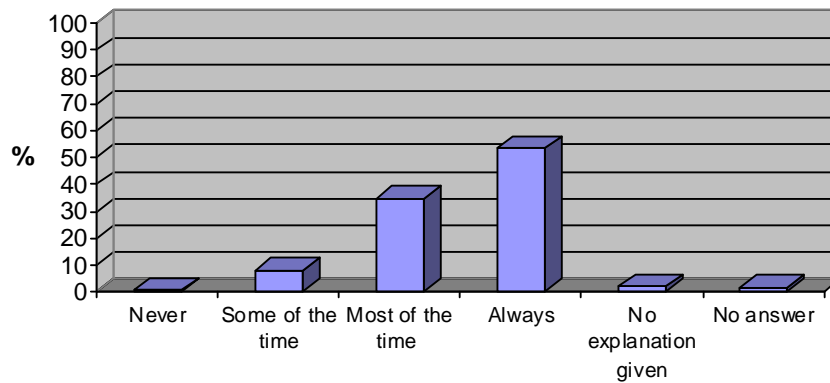
The survey also asked about users understanding of the explanations given to them about their care whilst on the ward. Just over half of respondents (53%) felt that they always understood the explanations given to them (this is a decrease of 12% compared to the last survey). However this time a higher proportion compared to last said they understood explanations most of the time (35%). One respondent said they never understood explanations given to them. Only 5% of respondents suggested ways of making their hospice's explanations clearer (for suggestions see the 5.4 textual comments sections in this report). 71% of inpatients felt that they were always given the opportunity to ask questions when they wanted to, and the opportunity was given most of the time to 19%, which is helpful to a patient if an explanation isn't understood. One respondent felt they were never given the opportunity to ask questions. The patients' experiences of always being given the opportunity to ask questions was very varied between the individual benchmark hospices (ranging from 27%-91%).

The majority of inpatients said they were given the time they needed to make decisions about their care, 63% felt that they were always given enough time to make a decision, and 21% felt they had enough time most of the time. Four respondents (2%) felt they were never given enough time to make decisions about their care. The patient experience of always having enough time for decision making was varied among the individual benchmark hospices (range: 23%-81%).

Q6 Did you understand the explanations given to you about your treatment and care?

	N	Average (%)	Range (%)
Never	1	0.5	0.0 – 2.3
Some of the time	15	7.8	1.8 – 18.2
Most of the time	67	34.7	19.0 – 50.0
Always	103	53.4	20.5 – 66.1
No explanation given	4	2.1	0.0 – 6.8
No answer	3	1.6	0.0 – 2.4
Total	193	100	

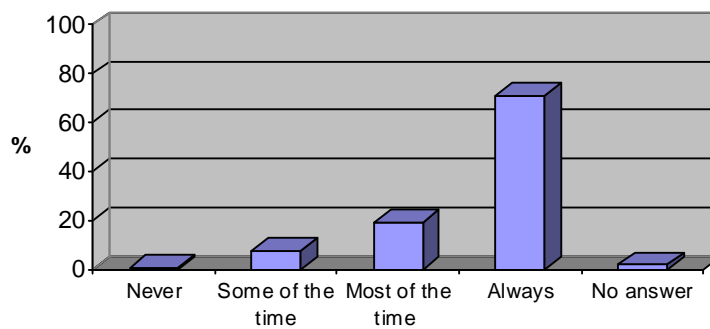
Q6 Overall, did you understand the explanations given to you about your treatment and care?



Q7 Did you have the opportunity to ask questions when you wanted to?

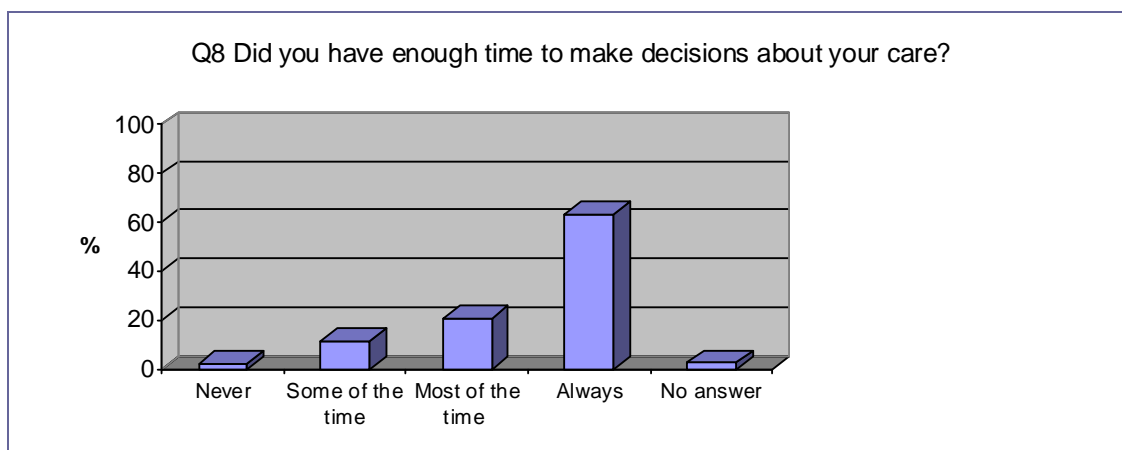
	N	Average (%)	Range (%)
Never	1	0.5	0.0 – 2.0
Some of the time	15	7.8	0.0 – 31.8
Most of the time	37	19.2	9.5 – 36.4
Always	137	71.0	27.3 – 90.5
No answer	3	1.6	0.0 – 4.5
Total	193	100	

Q7 Did you have the opportunity to ask questions when you wanted to?



Q8 Did you have enough time to make decisions about your care?

	N	Average (%)	Range (%)
Never	4	2.1	1.8 – 3.9
Some of the time	22	11.4	0.0 – 43.2
Most of the time	40	20.7	11.9 – 27.3
Always	122	63.2	22.7 – 81.0
No answer	5	2.6	0.0 – 4.5
Total	193	100	



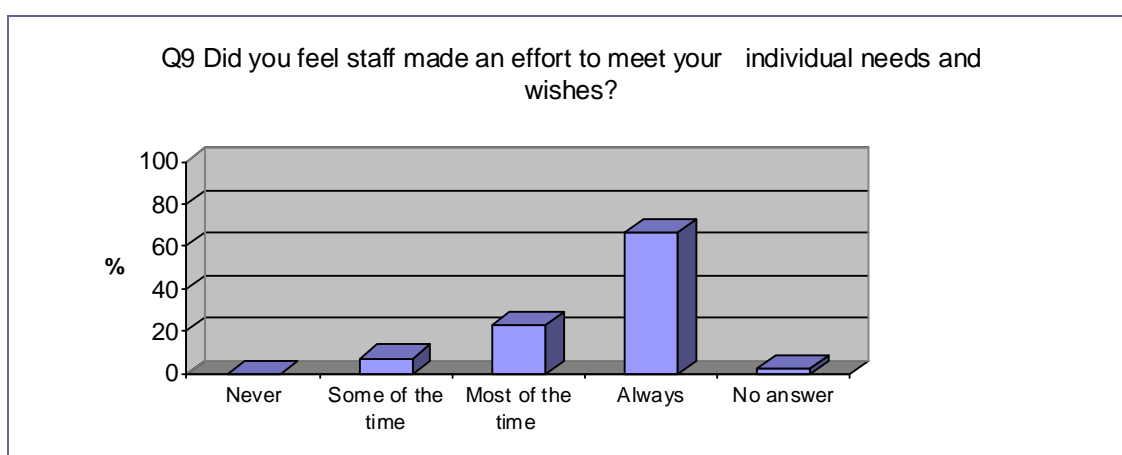
Views of Inpatients on the Support and Courtesy of Staff

A number of questions were asked in the survey about inpatient views on the support and courtesy of the staff looking after them on the ward. Generally respondents were positive about the support they received from staff. Two thirds of respondents (67%) felt that staff always made an effort to meet their individual needs and wishes (which is a lower proportion than last time, a decrease of 13%). A higher proportion this time (23%) felt they made the effort most of the time. None of the respondents felt that staff never made an effort at all.

The vast majority of inpatients generally felt that staff were always respectful. 90% felt they were always treated with respect, and 8% most of the time. None felt they were never treated with respect. 78% of respondents felt that their privacy needs were always met, for example when being examined or during discussions with staff. This is a 10% increase on last survey where the question asked was about whether their privacy was respected. 15% felt their privacy needs were met most of the time and one respondent felt their privacy needs were never met.

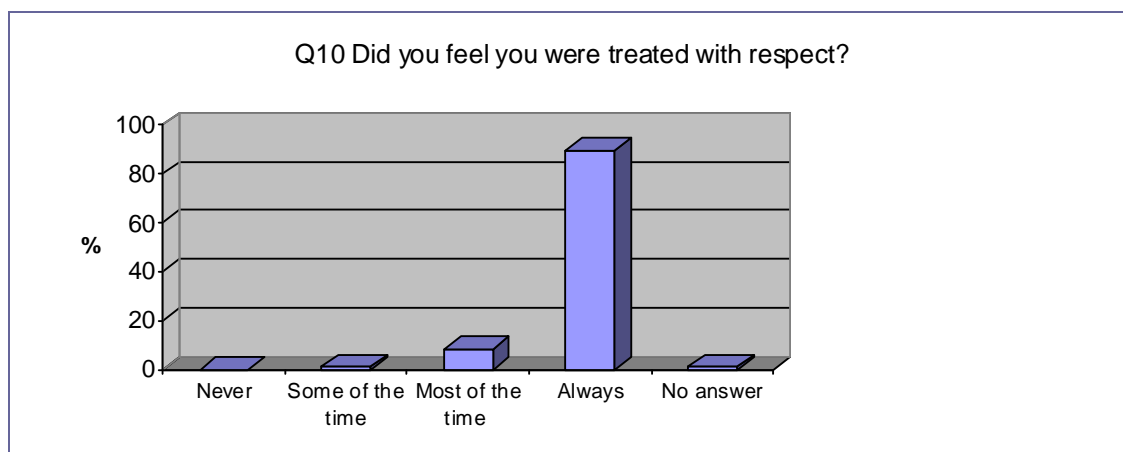
Q9 Did you feel staff made an effort to meet your individual needs and wishes?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	14	7.3	0.0 – 29.5
Most of the time	45	23.3	11.9 – 45.5
Always	129	66.8	25.0 – 88.1
No answer	5	2.6	0.0 – 5.4
Total	193	100	



Q10 Did you feel you were treated with respect?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	2	1.0	0.0 – 2.4
Most of the time	16	8.3	2.4 – 22.7
Always	173	89.6	75.0 – 95.2
No answer	2	1.0	0.0 – 3.9
Total	193	100	



Q11 Did you feel your privacy needs were met e.g. when being examined or during discussions with staff?

	N	Average (%)	Range (%)
Never	1	0.5	0.0 – 2.0
Some of the time	7	3.6	0.0 – 13.6
Most of the time	29	15.0	3.9 – 45.5
Always	151	78.2	34.1 – 95.2
No answer	5	2.6	0.0 – 6.8
Total	193	100	



Inpatient Facilities and Services

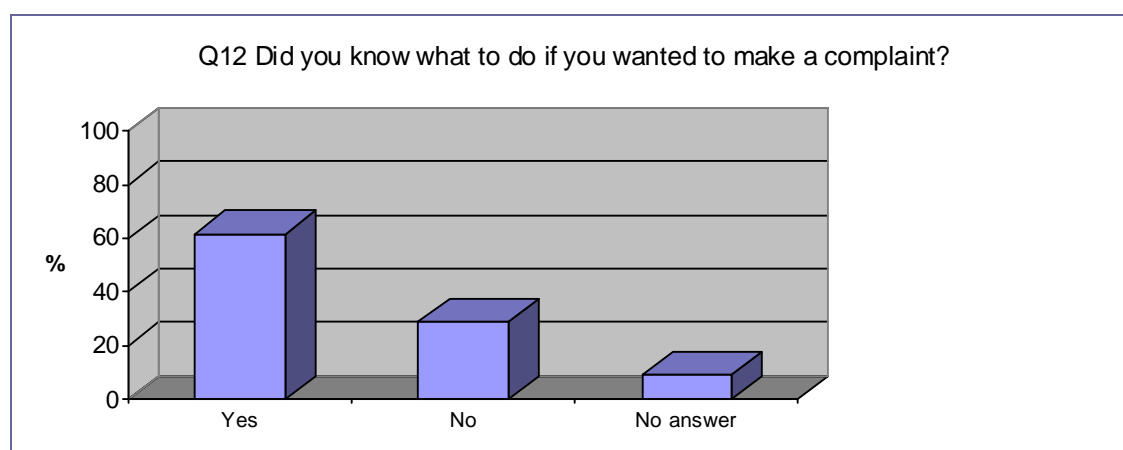
The survey asked a range of questions about how patients rate the facilities and services available to inpatients in their hospice. It asked about awareness of how to make a complaint, what they thought about the quality of the catering, access to food other than at meal times, and also views on the hospice and ward buildings themselves by asking questions about the general environment, surroundings and the cleanliness of the premises.

62% of respondents were aware of how to make a complaint compared to 29% who were not (this is a decrease of awareness by 11% compared to the last survey). The responses to awareness of the complaints procedures were quite broad ranging for the individual benchmark hospices (between 25%-73% were aware).

When asked to rate the facilities and services the following were viewed by the majority to be of a high standard and rated as excellent: the cleanliness of the premises (81%) and the general environment and surroundings (88%). Slightly less prevalent ratings of excellence applied to the quality of the catering (64%) and access to food other than at meal times (58%). The proportion of respondents who rated these facilities and services as excellent was higher than the last survey for cleanliness, access to food outside meal times, and the general environment and surroundings (with increases of 9%, 5% and 8% respectively). However ratings of excellent were quite variable, among the benchmark hospices individually for all of these aspects (particularly this time for cleanliness and access to food outside meal times) but there is also room for improvement for some hospices in all these areas. Respondents were invited to make further comments on these facilities and services which can be found in the 5.4 textual comments sections of this report.

Q12 Did you know what to do if you wanted to make a complaint?

	N	Average (%)	Range (%)
Yes	119	61.7	25.0 – 73.2
No	56	29.0	15.7 – 63.6
No answer	18	9.3	7.1 – 11.8
Total	193	100	



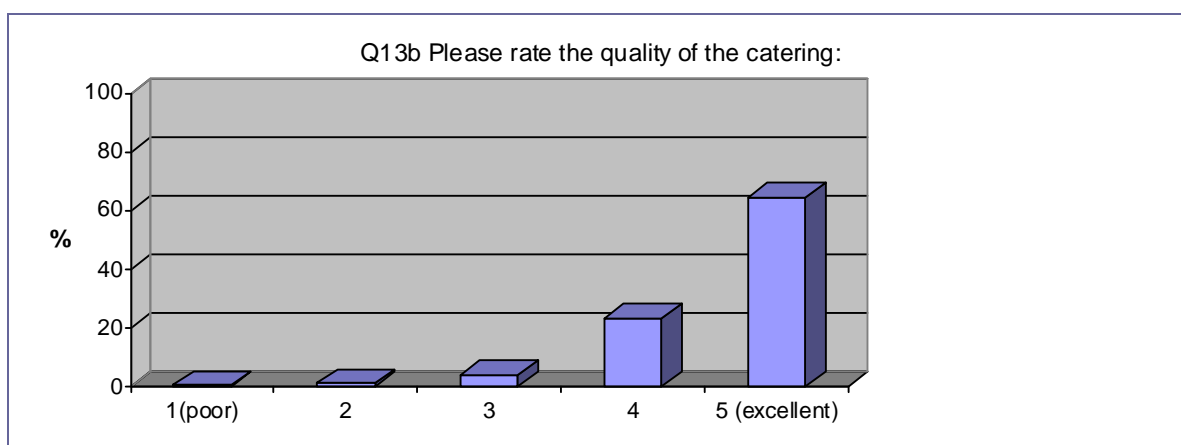
Q13a Please rate how clean the hospice was:

	N	Average (%)	Range (%)
1. Poor	1	0.5	0.0 – 2.0
2.	0	0.0	0.0 – 0.0
3.	1	0.5	0.0 – 2.3
4.	30	15.5	9.5 – 31.8
5. Excellent	157	81.3	61.4 – 90.5
No answer	4	2.1	0.0 – 4.5
Total	193	100	



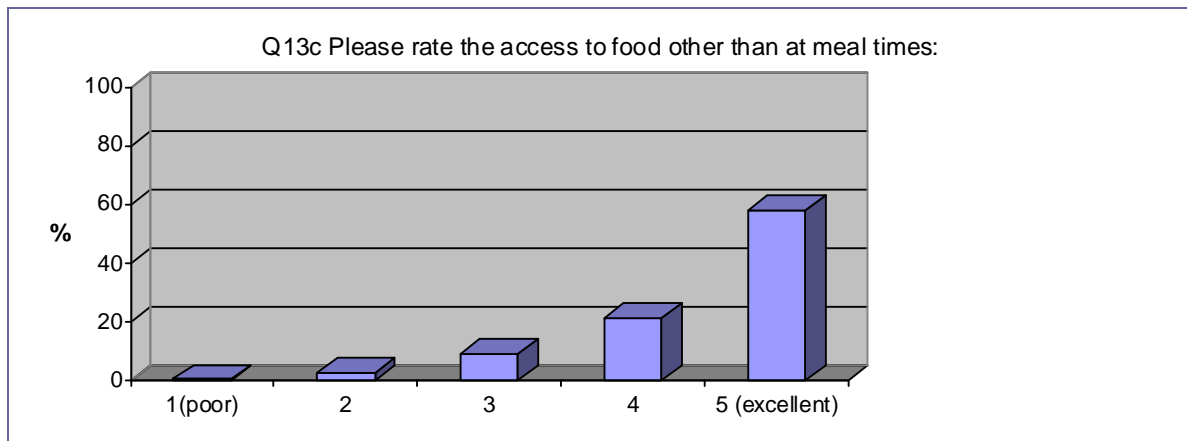
Q13b Please rate the quality of the catering:

	N	Average (%)	Range (%)
1. Poor	1	0.5	0.0 – 2.0
2.	2	1.0	0.0 – 2.3
3.	8	4.1	1.8 – 9.1
4.	45	23.3	13.7 – 28.6
5. Excellent	124	64.2	56.8 – 70.6
No answer	13	6.7	4.5 – 9.8
Total	193	100	



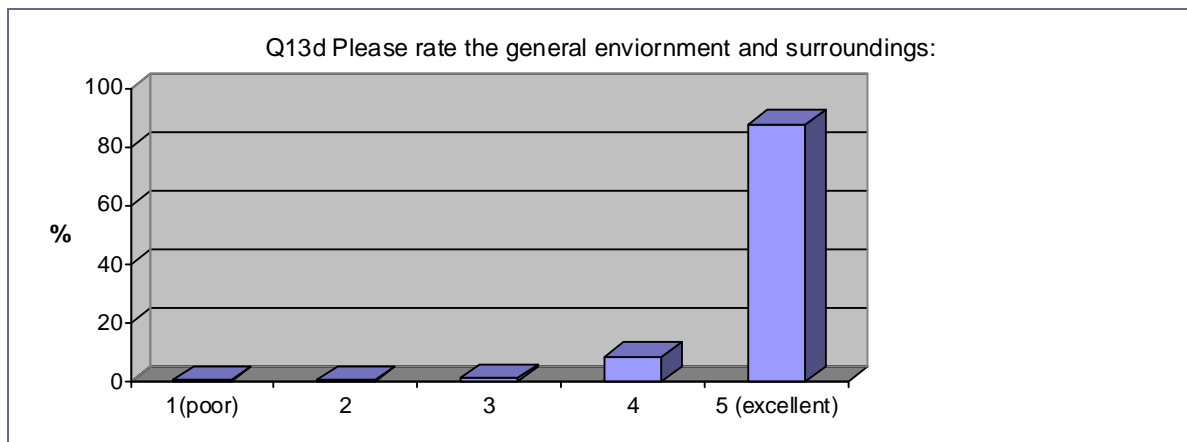
Q13c Please rate the access to food other than at meal times:

	N	Average (%)	Range (%)
1. Poor	1	0.5	0.0 – 2.0
2.	5	2.6	0.0 – 6.8
3.	17	8.8	2.4 – 18.2
4.	41	21.2	9.8 – 34.1
5. Excellent	112	58.0	36.4 – 70.6
No answer	17	8.8	4.5 – 12.5
Total	193	100	



Q13d Please rate the general environment and surroundings:

	N	Average (%)	Range (%)
1. Poor	1	0.5	0.0 – 2.0
2.	1	0.5	0.0 – 2.4
3.	2	1.0	0.0 – 2.4
4.	16	8.3	0.0 – 20.5
5. Excellent	169	87.6	75.0 – 95.2
No answer	4	2.1	0.0 – 4.5
Total	193	100	

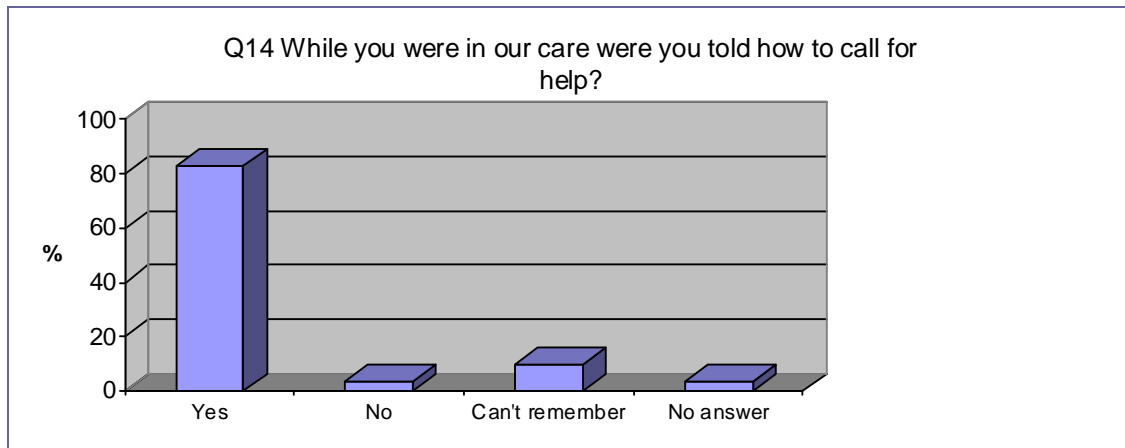


Inpatients Calling for Assistance

The majority of inpatients (83%) were told how to call for help while they were in hospice care (7% less than the previous survey). 4% of respondents reported that they were not told, and 10% couldn't remember if they had been told (this was particularly high for one of the hospices). 20 respondents (10%) did not need to call for assistance, while they were an inpatient. Of those who did need to call for assistance the majority (71%) were always satisfied with the response they got, 20% were satisfied most of the time with the response. The answer to this question was quite varied between the individual hospices, with patients in some hospices being much happier with the response compared to others (40%-81%).

Q14 While you were in our care were you told how to call for help?

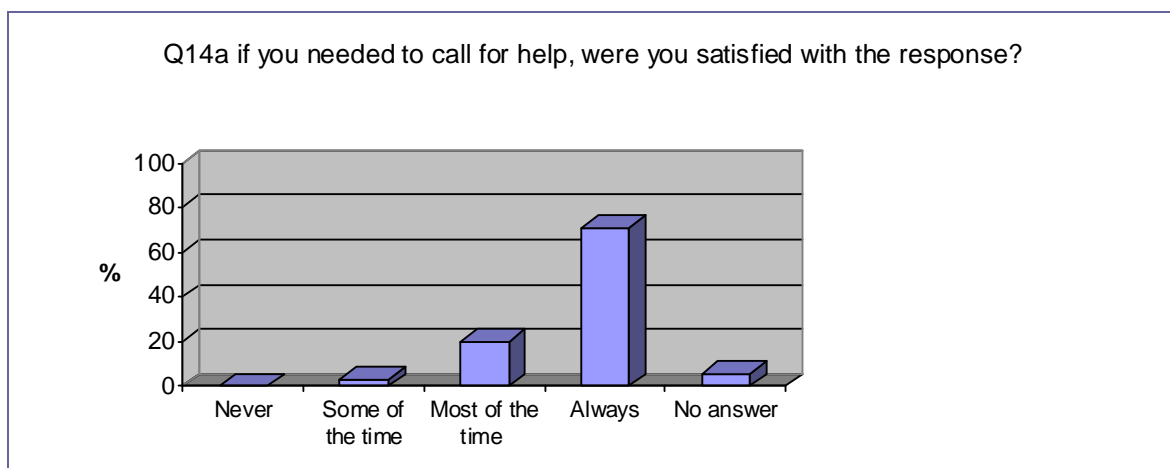
	N	Average (%)	Range (%)
Yes	160	82.9	38.6 – 98.2
No	7	3.6	0.0 – 13.6
Can't remember	19	9.8	0.0 – 43.2
No answer	7	3.6	1.8 – 5.9
Total	193	100	



Q14a If you needed to call for help, were you satisfied with the response?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	5	2.9	0.0 – 8.6
Most of the time	35	20.2	12.5 – 42.9
Always	123	71.1	40.0 – 80.9
No answer	10	5.8	3.9 – 8.6
Total	173	100	

Not applicable as did not need to call for help: 20

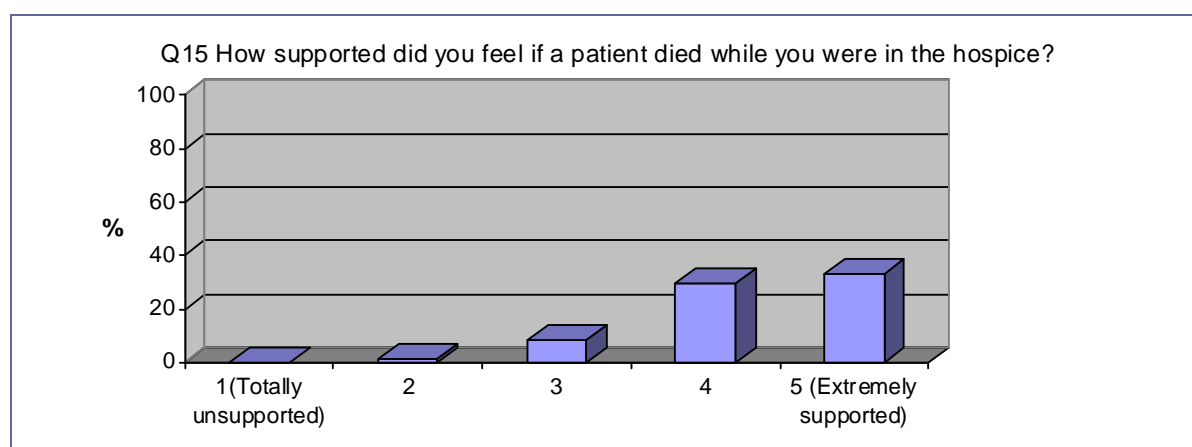


Support if Someone had Died

Inpatients were asked how supported they felt if a fellow patient died while they were in the hospice. Over half of the inpatients (58%) were not aware that others had died whilst they had been in the hospice. For those who had been/ or were made aware a third (33%) felt they had been extremely supported (this is a decrease of 15% compared to last years benchmark results) and almost the same proportion felt generally supported. No one felt they were totally unsupported by their hospice. However 27% of patients chose not to answer this question, which is the highest rate of non-completion compared to other questions in the inpatient survey and this is a slightly higher rate of non-response compared to last years survey. There was variation in the number who felt supported and in the number who answered depending on the hospice they stayed in.

Q15 How supported did you feel if a patient died while you were in the hospice?

	N	Average (%)	Range (%)
1. Totally unsupported	0	0.0	0.0 – 0.0
2.	1	1.2	0.0 – 5.0
3.	7	8.6	6.7 – 16.7
4.	24	29.6	16.0 – 46.7
5. Extremely supported	27	33.3	0.0 – 48.0
No answer	22	27.2	20.0 – 50.0
Total	81	100	
Not applicable as was not aware of anyone dying: 112			



5.3 Average Inpatients Results Overall (46 hospices)

The following results report the average responses of all participants aggregated together from all 46 hospices who took part in the inpatient questionnaire at discharge. The total number of completed questionnaires received from inpatients was 963 and all are included in the following results.

Service: Inpatient
N: 963

Q1 During your time on the ward, were you aware of a leaflet or booklet?

Yes:	No	Can't remember	No answer
635 (65.9%)	231 (24.0%)	55 (5.7%)	42 (4.4%)

Q2a If you looked at the leaflet or booklet, was it easy to understand?

Yes	No	Can't remember	No answer
583 (91.2%)	4 (0.6%)	20 (3.1%)	32 (5.0%)
Did not look at the leaflet or booklet: 38			
Not applicable: 286			

Q2b If you looked at the leaflet or booklet, was it helpful?

Yes	No	Can't remember	No answer
557 (87.3%)	2 (0.3%)	32 (5.0%)	47 (7.4%)
Did not look at the leaflet or booklet: 39			
Not applicable: 286			

Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

Yes	No	Can't remember	No answer
18 (2.8%)	478 (74.6%)	78 (12.2%)	67 (10.5%)
Did not look at the leaflet or booklet: 36			
Not applicable: 286			

Q3a While you were an inpatient did the staff involved in your care introduce themselves?

Never	Some of the time	Most of the time	Always	No answer
4 (0.4%)	39 (4.0%)	149 (15.5%)	751 (78.0%)	20 (2.1%)

Q3b While you were an inpatient did the staff involved in your care explain what they were doing?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	47 (4.9%)	161 (16.7%)	716 (74.4%)	37 (3.8%)

Q4 Did you have confidence in the staff who were caring for you?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	14 (1.5%)	107 (11.1%)	828 (86.0%)	12 (1.2%)

Q5 How satisfied were you with your involvement in planning your care?

Very dissatisfied	Not satisfied	Satisfied	Very satisfied	No answer
21 (2.2%)	17 (1.8%)	253 (26.3%)	643 (66.8%)	29 (3.0%)

Q6 Did you understand the explanations given to you about your treatment and care?

Never	Some of the time	Most of the time	Always	No explanation given	No answer
1 (0.1%)	51 (5.3%)	257 (26.7%)	617 (64.1%)	7 (0.7%)	30 (3.1%)

Q7 Did you have the opportunity to ask questions when you wanted to?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	34 (3.5%)	168 (17.4%)	736 (76.4%)	23 (2.4%)

Q8 Did you have enough time to make decisions about your care?

Never	Some of the time	Most of the time	Always	No answer
7 (0.7%)	49 (5.1%)	209 (21.7%)	660 (68.5%)	38 (3.9%)

Q9 Did you feel staff made an effort to meet your individual needs and wishes?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	36 (3.7%)	151 (15.7%)	748 (77.7%)	26 (2.7%)

Q10 Did you feel you were treated with respect?

Never	Some of the time	Most of the time	Always	No answer
0 (0%)	10 (1.0%)	49 (5.1%)	880 (91.4%)	24 (2.5%)


Q11 Did you feel your privacy needs were met e.g. when being examined or during discussions with staff?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	14 (1.5%)	94 (9.8%)	825 (85.7%)	28 (2.9%)

Q12 Did you know what to do if you wanted to make a complaint?

Yes	No	No answer
658 (68.3%)	224 (23.3%)	81 (8.4%)

Q13 Please rate the following by circling your response:

	1 =Poor  5 =Excellent					No answer
	1	2	3	4	5	
How clean the hospice was	3 (0.3%)	4 (0.4%)	14 (1.5%)	118 (12.3%)	795 (82.6%)	29 (3.0%)
The quality of the catering	6 (0.6%)	11 (1.1%)	37 (3.8%)	178 (18.5%)	679 (70.5%)	52 (5.4%)
Access to food other than at meal times	23 (2.4%)	13 (1.3%)	94 (9.8%)	150 (15.6%)	579 (60.1%)	104 (10.8%)
The general environment and surroundings	2 (0.2%)	6 (0.6%)	19 (2.0%)	96 (10.0%)	809 (84.0)	31 (3.2%)


Q14 While you were in our care were you told how to call for help?

Yes	No	Can't remember	No answer
879 (91.3%)	13 (1.3%)	35 (3.6%)	36 (3.7%)

Q14a If you needed to call for help, were you satisfied with the response?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	21 (2.4%)	149 (17.0%)	653 (74.3%)	55 (6.3%)
Did not need to call for help: 84				

Q15 How supported did you feel if a patient died while you were in the hospice?

1 =Totally unsupported  5=Extremely supported					No answer
1	2	3	4	5	
9 (2.2%)	6 (1.4%)	43 (10.4%)	81 (19.6%)	175 (42.3%)	100 (24.2%)
Not applicable as was not aware of anyone dying: 549					

5.4 Inpatient Textual Comments (46 hospices)

This section summarises inpatients' comments across all the hospices involved in the inpatient survey. Each participating hospice has also been given comments from their own patients who responded to the inpatient survey.

The questionnaire had space for patients to write in and elaborate on their answers to some of the 'tick box' questions and respondents were also asked to make some general comments at the end of the questionnaire if they wished to. Comments were received from respondents about information, the care staff, explanations about care, catering, facilities, and the general environment of the hospice. Comments relating to confidence in the staff (280 comments), hospice facilities such as catering and hospice surroundings (224) and general comments on suggestions to develop the service (320) were particularly numerous.

The majority of comments were highly favourable and a selection of these are referred to in the summary of comments that follows. This summary focuses mainly on comments that identify issues for hospices to act upon and it should be noted that the majority were made by one or two people only. Overall there were only 272 (23%) out of a total of 1189 comments that identified issues for hospices to address.

Information leaflets and booklets (Q2)

Respondents were asked to comment on anything they could not understand or found unhelpful or incorrect in their hospice's leaflet or booklet, as well as any suggestions they had to improve it. Some respondents commented that they had not seen a leaflet or booklet or didn't know about it. Others said they could not read it because of reasons like they were partially sighted or they felt too unwell. A few respondents said they had been in the hospice before and didn't feel they needed to read it.

Other comments regarding the information leaflet or booklets included visiting times not being clear, too much text, too much information to take in at one go, and one respondent felt the information was 'common sense'. Respondents noted that information about the day room, menu options, availability of snacks, times of Doctors rounds were not correct in their hospice leaflet and another said the pages were out of sequence.

Comments regarding what else could be in the leaflet or booklet included some positive comments praising the information as it is, such as it was 'comprehensive', and 'very explanatory'. Others did make some suggestions for other information that could be a useful addition to the leaflet or booklet. This included more information on transport, toilet facilities, maps or plans of the hospice, menus and meal times, visitor information, medication and equipment, newspapers, internet access, telephone numbers, relevant state benefits and other connected services that could offer assistance. It was also suggested by some that the leaflet should be more available.

Care staff (Q4)

The comments about confidence in staff were overwhelmingly positive, saying that the care was exemplary and couldn't be bettered and describing staff as 'caring', 'excellent', 'friendly', 'wonderful' people who had understanding and time for their patients. A few compared the care of staff in the hospice to be better than that received in hospital. Other staff such as cleaners, chefs and volunteers were also praised by some as well as the care staff. Some patients said:

'The staff were always ready to help. They always found time to listen, which meant a lot'

'The caring included interest, friendship, laughter, concern and time. I return home relaxed and very impressed'

'The staff have a wonderful aura about them, they are truly nursing angels'

Some respondents said there were exceptions with a few staff not being as friendly and helpful. One respondent described a couple of them in their hospice as 'abrupt and authoritarian' and another said one or two could be more compassionate. Some respondents commented that there was sometimes slow response to care (particularly if staff were busy), so a few respondents thought more staff were needed. Regarding the more negative comments one respondent thought more care should be taken to make sure mobility items were readily available. Another said they didn't get the daily leg exercises they needed, someone else observed that care staff had difficulty in using the hoist or sling, difficulty fitting urinary bags, and another felt that they had too many care staff washing them and this made them feel intimidated. Other comments mentioned were occasions when patients were left without food, not provided with drinks, and little continuity of care at handover. However others noted that staff handover was smooth and didn't impact on their continuity of care.

Care planning (Q5)

Only a few comments were made in relation to patient involvement in care planning but responses did give an insight into patients' thoughts about their involvement in care. Some wrote that they were not involved, or didn't want to be involve in their care planning and preferred to leave this to the care staff or to their carer or relative. Some didn't want to know anything about their illness or any results. On the other hand others felt too many decisions were out of their control and wanted to be more involved. Therefore views on involvement in care varied depending on the individual concerned. A few respondents felt that a better explanation of care was needed from early on into order to have a better understanding of their plan of care and progress. Another respondent felt that it was confusing to have a number of different people involved in the planning of their care.

Explanations about care (Q6)

Some patients said they were happy with explanations given and thought they were clear, other patients found explanations given more difficult to understand sometimes because of impaired hearing or because of their illness, others just found it hard to remember. In these cases suggestions were to have some written information or to have a reminder or second visit to confirm patient understanding. Some patients wanted clearer explanations about medical matters in particular. For example medical jargon and terminology should be explained or different language used. Others felt explanations about medication and reasons for changes in medication and doses should be clearer.

Cleanliness of premises, catering, access to food other than at meal times, general environment and surroundings (Q13)

This section of the questionnaire prompted many positive comments and some could not fault the hospice facilities. Some positive comments included:

'The hospice is run very well and is as comfortable as a home. The staff are kindness itself. This includes catering, cleaning staff and volunteers. Everyone was so kind and considerate'

'As good as any 5 star hotel. When ill, and needing treatment couldn't be in a better place, in fact the only place to be when feeling poorly'.

'I felt privileged to be able to stay there, everything was so comfortable'

The facilities and service at the hospice exceeded the expectation of some patients, commenting on the nice gardens, food and welcoming environment. Some also felt their dietary requirements were well catered for. However some patients remarked on some aspects which were not rated so highly. A high proportion of the more negative comments related to the catering, but also referred to other areas of the hospice:

Catering - Some respondents felt the food was predictable, cheap from a tin or packet, was bland, lack of choice, and some questioned the portion size (either being too large or too small). One respondent suggested that they could be given a little more time to eat their meal, and one suggested meals were served too early. Another

suggested a greater use of gravy or sauces with food would be helpful to patients who find it hard to swallow or chew. Some of the respondents said they were unable to eat the food due to their illness.

Access to food other than at mealtimes – Some respondents said they were not aware that they could access food at other times or didn't know how to, and some thought that it wasn't necessary; others felt that a extra snack or drink outside meal times would be nice if required. It was also suggested that food should be provided to visitors, a vending machine or small shop were suggested to cater for them.

Premises – Some commented that the hospice was a relaxing and tranquil place. A few small comments were made regarding the buildings, furniture and facilities available. Some of these related to the ward environment. One respondent would have liked access to a television when in bed, another felt their ward wasn't cleaned often enough. Renovations and building work had a negative impact on the environment for some; others welcomed some refurbishment as they felt the hospice surroundings were looking 'tired' or 'dated'. Layout was an issue for one respondent regarding access to facilities in the bathroom. Another found it difficult to walk around the outside areas of their hospice because of uneven paving slabs.

Overall comments (Q15)

At the end of the questionnaire inpatients were asked if they had any more comments or suggestions to help their hospice develop its services. Many inpatients took this opportunity to make remarks about their hospice stay overall, and the majority of these were favourable:

'Carry on as you are. The staff should be told what a wonderful job they are doing and how much they are appreciated'

'I was so happy whilst in the hospice. I feel you can't improve on perfection'

'The hospice is a wonderful place and I can't praise it enough. The staff made everything so comfortable and not a bit like being in hospital'

Among the remaining comments the same overall problems were raised that had appeared in earlier sections of the questionnaire, such as, food, noise, staff numbers, transport, lack of information, television facilities, and catering for visitors. However, patients also raised new issues at the end of the questionnaire. The more frequent issues were the problem of lights being on at night, buzzers being hard to activate, televisions being intrusive (use of headphones suggested), more parking facilities, and more things to do (for respite patients in particular who sometimes found their stay a lonely experience if other patients around them were very ill). Some patients also commented on hospice practices when a fellow patient had passed away, which may have been due to the previous question being about support when a patient had died. Some additional issues were raised about more fundraising schemes for hospices and provision of a day room.

The Questionnaire (Q16)

There were many complimentary comments about the survey indicating that the questionnaire was easy to follow and to complete, and they could see that such a survey was needed to monitor performance. One respondent who was partially sighted liked the paper the questionnaire was printed on as the contrast between the black text and light blue background made it easy to read.

It was mentioned here when a relative or carer had completed the questionnaire on the patient's behalf and it was suggested that the questionnaire could be changed slightly to accommodate this to make it clear who is responding. Some thought the content and length of the questionnaire was adequate but others felt it was too long. On the other hand others thought it could be more detailed, some suggestions were to include questions on the attitude and friendliness of the staff, and questions on changing medication.

Others had comments on specific questions. One respondent commented that 'passed away' may be a less aggressive term to use rather than 'died' and another thought that a 'not applicable' option could be added in some of the questions. Another thought that there were too many questions on the information booklet and thought questions on the level of care were more important.

6. Discussion

A version of this report is given to each hospice participating in the survey which also includes their own results for their hospice. This enables each hospice to look at their results and compare themselves against the benchmark hospice results and results overall for all participating hospices. Individual hospices can then benefit from seeing how well they 'fit' with other hospices who took part and against those receiving a high response from the survey.

Aggregated results for the benchmark hospices and all participating hospices overall were very positive for both the daycare and inpatient ward settings. They were both considered excellent and of a high standard in a number of broad areas. The highest praise was shown for the staff that worked in the hospice, with the vast majority of respondents always having confidence in the staff caring for them, feeling that they always treated them with respect, and always made an effort to meet their individual needs and wishes as well as meet any privacy needs. Respondents reported that care staff would always introduce themselves when they met and there were many written comments about the friendliness and helpfulness of the staff. Patients were also highly complimentary about information leaflets and booklets provided by hospices to patients about their services, in terms of their helpfulness and ease to read. However just over a quarter of respondents did not have access to or were not given a information leaflet or booklet.

Other areas of care were more varied in terms of their response, and although mainly positive, views were a reflection of individual circumstances and preferences. For example views on satisfaction with involvement in care planning were mixed as some wanted to be more involved, others observed that they were not involved in the planning of their care and others said they wanted to leave this to the staff. Similarly with explanations of care some wanted to know more or for explanations to be in clearer language, while others didn't want to know about issues concerning their illness. Mixed views were also received when rating services and facilities provided in the hospices. For example there was a broad range of views expressed about the catering and food provided with the majority finding this to be excellent but some commented that improvement could be made to the quality and the choice on offer. Activities provided within daycare services were particularly noted as an area whereby there could be a wider variety of activities in order to cater for different interests. The cleanliness, general environment and surroundings of the hospices were very pleasing to the vast majority of patients. The main areas of concern for a few were noise within some inpatient wards, space in daycare settings, and the 'dated' appearance of some hospices and their furnishings, although others were not happy with some aspects of new refurbishments within some daycare units. The majority of daycare patients were also happy with transport services provided by the hospices, including praise for the drivers, but there were some comments made indicating areas for potential improvement e.g. the vehicles used.

Aspects of hospice care that were least satisfactory were related to support when a patient had died or had been discharged (daycare only). Not all respondents were aware of patients who had passed away, but for those that were aware fewer than half of respondents felt they were well supported when this happened. Only half of daycare patients were aware of anyone being discharged from daycare but for those who were aware only a third felt they were extremely supported. Respondents were also less likely to answer these questions compared to others.

The survey therefore highlighted some different priorities and needs for individuals as well as daycare patients and inpatients more broadly. Different levels of satisfaction may be due to the different nature of care and treatment inpatient and daycare patients receive, inpatient care being more complex and staying in the hospice for a longer period of time rather than the short visits provided by daycare services. However it is important to recognise that despite these differences the level of satisfaction with all of these areas was extremely high for both inpatient and daycare patients.

The results for benchmark hospices were very similar to the average results for all hospices for daycare. However the results were more variable between the results for the inpatient results, which is probably due to the lower number of hospices being included in the benchmark figures this time. The characteristics of individual benchmark hospices that were either rated particularly satisfactory or unsatisfactory then have more of an impact on the average results. Low numbers in the inpatient benchmark indicates that reaching a response of 40 or more completed questionnaires was harder to achieve within the inpatient units of the hospices that participated in the survey this year.

Some comparison was made between the results for the 2008/09 survey and the previous survey in 2006/07. Overall satisfaction with daycare and inpatient services remains extremely high, although a slight, but not significant, dip in levels of extreme satisfaction can be observed across the years. The difficulty with such a comparison of the benchmark results in particular is that year on year different hospices participate and the number of hospices achieving the benchmark will vary and this needs to be taken into account when interpreting the results over time.

7. Considerations for the Future

- This survey has been repeated for a third time to seek views of patients on the quality of the treatment and care provided as required by the Care Quality Commission. Given the similar nature of the results overall to previous years there is confidence in these results, indicating that it is worthwhile to continue.
- It is recommended that the survey should be repeated so that individual hospices participating in the survey can measure change in their quality of care over time for their own hospice, as well as being alerted to issues more widely regarding patient satisfaction with hospice care.
- The survey results are beneficial to the hospices taking part as it has allowed them to legitimately identify areas for improvement in their hospice and take appropriate action. This action may involve further investigation of the issue by consultation with patients. The consultation may be in the form of more qualitative methods of research, such as focus groups or meetings with patients and staff to discuss the issue.
- Key areas identified within some hospices were catering services, support when a patient had been discharged or died, daycare transport services, activities, user involvement in planning of care and treatment, information giving and understanding. Participating hospices should be encouraged to develop their own action plans where there is scope for improvement, identified from their individual results.
- If the survey is to be repeated the questionnaire content should be reviewed to ensure the question topics are applicable to current hospice service provision, and consider the need for inclusion of any new topics or recipients of the questionnaires. The questionnaire format and layout should also be revisited to ensure its ease to complete once printed off by individual hospices.
- While improvements have been made in systematically measuring the response rates for participating hospices, there was partial compliance with just over 50% of hospices collecting and providing the relevant information. Continuing to work with hospices to collect this information should result in a more complete and accurate picture of patients' willingness to complete the survey, which is still needed.

Daycare questionnaire –2008

Hospice code

Here at (enter the name of the hospice here), we are keen to make sure that the services we provide meet your needs. Please fill in this short questionnaire about your experience with us. You do not have to give your name. Please give honest responses, as they will give us important information to help us plan for the future.
Many thanks for your time.

1 Before or during your time in daycare at (enter name of hospice here), were you aware of a leaflet or booklet called (enter name of information here)?

(We have attached a copy of the front page of this leaflet or booklet to remind you which one we are asking about.)

- No ☐ Go to question 3.
Yes ☐ Go to question 2.
Can't remember ☐ Go to question 3.

2 If you looked at the leaflet or booklet

A Was the leaflet or booklet easy to understand?

No ☐

Yes ☐

Can't remember ☐

Did not look at the leaflet or booklet ☐

If you ticked 'No', please give more details.

.....
.....

B Was the leaflet or booklet helpful?

No ☐

Yes ☐

Can't remember ☐

Did not look at the leaflet or booklet ☐

If you ticked 'No', please give more details.

.....
.....

Daycare questionnaire –2008

Hospice code.....

C Was there anything in the leaflet or booklet that was not correct?

No ☐

Yes ☐

Can't remember ☐

Did not look at the leaflet or booklet ☐


If you ticked 'Yes', please give more details.

.....
.....

D Do you have any suggestions for other information that should be included in the leaflet or booklet?

.....
.....

3 Did you feel anxious at the beginning of your first visit to Daycare? (Please tick the box closest to your view.)

Not at all anxious  Extremely anxious

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

Can't remember ☐

4 Did you feel anxious at the end of your first visit to daycare? (Please tick the box closest to your view.)

Not at all anxious  Extremely anxious

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

Can't remember ☐

5 Was there anything we could have done to relieve your anxiety?

.....
.....

6 Did you use transport organised by the hospice?

Yes ☐

No ☐

(If 'No', please go straight to question 8.)

Hospice code.....

7 If you used hospice transport, please circle the score you would give the following.

Poor —————> Excellent

Whether you were picked up on time	1	2	3	4	5
Comfort of journey	1	2	3	4	5
Safety of journey	1	2	3	4	5

Do you have any more comments on the hospice transport?

.....
.....

8a While you were in daycare at (enter the name of the hospice here), did the staff involved in your care introduce themselves?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

8b while you were in daycare at (enter the name of the hospice here), did staff explain what they were doing?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

9 Did you have confidence in the staff who were caring for you?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

Do you have any more comments about this?

.....
.....

Hospice code.....

10 How satisfied were you with your involvement in planning your care?

Very dissatisfied ☐

Not satisfied ☐

Satisfied ☐

Very satisfied ☐

If you were not satisfied, do you have any suggestions as to how we could involve you more?

.....
.....

11 Did you understand the explanations given to you about the care provided while you were at daycare? (This does not include the care provided by your GP or hospital)

Never ☐

Some of the time ☐

Most of the time ☐


Always ☐

No explanations were given ☐

Is there any way we can make our explanations clearer?

.....
.....

12a How supported did you feel when a group member had been discharged? (Please tick the box closest to your view.)


Totally unsupported  Extremely supported

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

This does not apply to me as no-one had been discharged while I had been at daycare. ☐

Hospice code.....

12b How supported did you feel when a group member had died? (Please tick the box closest to your view.)

Totally unsupported  Extremely supported

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

This does not apply to me as no-one died while I had been at daycare. ☐

13 Did you have the opportunity to ask questions when you wanted to?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

14 Did you feel staff made an effort to meet your individual needs and wishes?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

15 Did you feel you were treated with respect?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

16 Did you feel your privacy needs were met, for example, when being examined or during discussions with staff?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

17 Did you know what to do if you wanted to make a complaint?

No ☐

Yes ☐

Hospice code.....

18 Please rate the following by circling your response.

Poor  Excellent

How clean the hospice was	1	2	3	4	5
The quality of the catering	1	2	3	4	5
Activities available for you to take part in	1	2	3	4	5
The general environment and surroundings	1	2	3	4	5

Do you have any more comments on the above?

.....
.....

19 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

Do you have any more comments about this?

.....
.....

20 Do you have any more comments or suggestions to help us improve our daycare service? (Please write below.)

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

21 Do you have any comments on the content or style of this questionnaire?

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

Hospice code.....

Anonymous results of this survey and any actions it has led to will be available (Enter feedback details as appropriate for your hospice)

**Please return the filled-in questionnaire in the prepaid envelope or send it to:
CHSS, George Allen Wing, Cornwallis Building, University of
Kent, Canterbury, Kent CT2 7NF.**

If you feel we could learn from hearing more about aspects of your care where you were not entirely satisfied or that you found particularly helpful, please call (enter details of daycare clinical manager here).

Thank you again for your help.



Here at **enter the name of the hospice here**, we are keen to make sure that the services we provide meet your needs. Please fill in this short questionnaire about your experience with us. You do not have to give your name. Please give honest responses, as they will give us important information to help us plan for the future.
Many thanks for your time.

1 During your time at **enter name of hospice here**, were you aware of a **leaflet or booklet** called (**enter name of information here**)?

(We have attached a copy of the front page of this leaflet or booklet to remind you which one we are asking about.)

- No ☐ Go to question 3.
Yes ☐ Go to question 2.
Can't remember ☐ Go to question 3.

2 If you looked at the **leaflet or booklet**

- a Was it easy to understand?
No ☐
Yes ☐
Can't remember ☐
Did not look at the **leaflet or booklet** ☐

If you ticked 'No', please give more details.

.....
.....

- b Was the **leaflet or booklet** helpful?
No ☐
Yes ☐
Can't remember ☐
Did not look at the **leaflet or booklet** ☐

If you ticked 'No', please give more details.

.....
.....

Inpatient questionnaire- 2008

Hospice code

c Was there anything in the leaflet or booklet that was not correct?

No ☐

Yes ☐

Can't remember ☐

Did not look at the leaflet or booklet ☐

If you ticked 'Yes', please give more details.

.....
.....

d Do you have any suggestions for other information that should be included in the leaflet or booklet?

.....
.....

3a While you were in enter name of hospice here, did the staff involved in your care introduce themselves?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

3b While you were in enter name of hospice here, did the staff involved in your care explain what they were doing?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

4 Did you have confidence in the staff who were caring for you?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

Do you have any more comments about this?

.....
.....

5 How satisfied were you with your involvement in planning your care?

Very dissatisfied ☐

Not satisfied ☐

Satisfied ☐

Very satisfied ☐

If you were not satisfied, do you have any suggestions as to how we could involve you more?

.....
.....

6 Did you understand the explanations given to you about your treatment and care?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

No explanations were given ☐

Is there any way we can make our explanations clearer?

.....
.....

7 Did you have the opportunity to ask questions when you wanted to?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐


8 Did you have enough time to make decisions about your care?

Never ☐

Some of the time ☐

Most of the time ☐

Always ☐

9 Did you feel staff made an effort to meet your individual needs and wishes?Never ☐Some of the time ☐Most of the time ☐Always ☐**10 Did you feel you were treated with respect?**Never ☐Some of the time ☐Most of the time ☐Always ☐**11 Did you feel your privacy needs were met, for example, when being examined or during discussions with staff?**Never ☐Some of the time ☐Most of the time ☐Always ☐**12 Did you know what to do if you wanted to make a complaint?**No ☐Yes ☐**13 Please rate the following by circling your response.**Poor  Excellent

How clean the hospice was	1	2	3	4	5
The quality of the catering	1	2	3	4	5
Access to food other than at mealtimes	1	2	3	4	5
The general environment and surroundings	1	2	3	4	5

Do you have any more comments on the above?

.....

14 While you were in our care were you told how to call for help?

No ☐

Yes ☐

Can't remember ☐

14a If you needed to call for help, were you satisfied with the response?

Never ☐


Some of the time ☐

Most of the time ☐

Always ☐

Did not need to call for help ☐

**15 How supported did you feel if a patient died while you were in the hospice?
(Please tick the box closest to your view.)**

Totally unsupported  Extremely supported

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

This does not apply to me as I was not aware of anyone dying while I was in the hospice. ☐

16 Do you have any more comments or suggestions to help us develop our services?

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

17 Do you have any comments on the content or style of this questionnaire?

.....
.....

Anonymous results of this survey and any actions it has led to will be available(Enter details as appropriate for your hospice)

**Please return the filled-in survey in the prepaid envelope or
send it to:**

**CHSS, George Allen Wing, Cornwallis Building, University of
Kent, Canterbury, Kent CT2 7NF.**

If you feel we could learn from hearing more about aspects of your
care where you were not entirely satisfied or that you found
particularly helpful, please call [enter details of inpatient clinical
manager here](#).

Thank you again for your help.



Appendix C

Questionnaire Amendments – 2008/09 Survey

Small amendments were made to parts of some questions in the day-care and in-patient questionnaires for the 2008/09 survey, with help from the Plain English Campaign. These amendments are presented in the tables below.

Day Care Questionnaire

	2006/07 Survey	2008/09 Survey
Q9	Overall, did you have confidence in the staff who were caring for you?	'Did you have confidence in the staff who were caring for you?'
Q10	Overall, how satisfied were you with your involvement in planning your care?	How satisfied were you with your involvement in planning your care?
Q11	Overall, did you understand the explanations given to you about the care provided while you were at daycare?	Did you understand the explanations given to you about the care provided while you were at daycare?
Q16	Did you feel your privacy was respected, for example, when being examined or during discussions with staff?	Did you feel your privacy needs were met, for example, when being examined or during discussions with staff?
Q18	Do you have any more comments?	Do you have any more comments on the above?
Q19		A new question was added: Do you have any more comments about this?

In-patient Questionnaire

	2006/07 Survey	2008/09 Survey
Q4	Overall, did you have confidence in the staff who were caring for you?	'Did you have confidence in the staff who were caring for you?'
Q5	Overall, how satisfied were you with your involvement in planning your care?	How satisfied were you with your involvement in planning your care?
Q6	Overall, did you understand the explanations given to you about your treatment and care?	Did you understand the explanations given to you about your treatment and care?
Q11	Did you feel your privacy was respected, for example, when being examined or during discussions with staff?	Did you feel your privacy needs were met, for example, when being examined or during discussions with staff?
Q14	Do you have any more comments?	Do you have any more comments on the above?

Appendix D

Response Statistics – All Help the Hospices Patient Surveys

		2004/05	2006/07	2008/09
No. of hospices participating	All hospices	53	53	52
	All Daycare	50	49	46
	All Inpatient	46	48	46
	Both services	43	44	40
	Just Daycare	7	5	6
	Just Inpatient	3	4	6
Returned questionnaires	Daycare	1398	1352	1259
	Inpatient	926	1052	963
	Total	2324	2404	2222
Average no. returns per hospice (min-max)	Daycare	28 (3-59)	28 (8-53)	27 (4-60)
	Inpatient	20 (4-59)	22 (2-58)	21 (2-56)
Response rate	Daycare	-	61% (from 28 hospices)	62% (from 25 hospices)
	Inpatient	-	49% (from 29 hospices)	41% (from 25 hospices)
No. hospices reaching the benchmark	Daycare	13	10	9
	Inpatient	5	9	4
No. of responses in the benchmark	Daycare	621	469	436
	Inpatient	237	424	193
Data collection period		7 months	8 months	8 months

Appendix E

Help the Hospices Patient Survey 2008/09 Final number of returned questionnaires - 20th March 2009

Hospice Name	Day-care Services	Inpatient Services	Total
Trinity Hospice - Blackpool	29	9	38
Hartlepool and District Hospice	27	23	50
Bolton Hospice	31	39	70
North Devon Hospice - Barnstaple	21	13	34
Dorothy House Hospice - Bradford-on-Avon	33	30	63
Halton Haven Hospice - Runcorn	8	6	14
St Catherine's Hospice - Crawley	15	29	44
St Andrew's Hospice - Grimsby	34	10	44
St Ann's Hospice - Manchester	51	30	81
St John's Hospice - Lancaster	8	6	14
St John's Hospice - Wirral	30	22	52
St John's Hospice - London	51	10	61
St Richard's Hospice - Worcester	50	0	50
Sue Ryder Care - Bedford	N/A	23	23
St Margaret's Somerset Hospice - Taunton	4	51	55
Wigan and Leigh Hospice	27	23	50
Wisdom Hospice - Rochester	50	10	60
The Shakespeare Hospice - Stratford-upon-Avon	21	N/A	21
St Luke's Kenton Grange Hospice - Harrow	44	42	86
The Rowans Hospice - Waterlooville	33	30	63
Pasque Charity - Luton	14	2	16
Hospice in the Weald - Tunbridge Wells	44	56	100
Meadow House Hospice - Southall	19	16	35
Southern Area Hospice Services - Newry	13	14	27
St Luke's Hospice - Sheffield	45	18	63
Willowbrook Hospice - Prescott	32	21	53
EllenorLions Hospice - Gravesend	41	25	66
St Gemma's Hospice -Leeds	6	39	45
Oakhaven Hospice Trust - Lymington	24	23	47
Primrose Hospice & Cancer Help Centre - Bromsgrove	15	N/A	15
Eden Valley Hospice - Carlisle	20	16	36
St Luke's Hospice - Plymouth	23	13	36
St Clare Hospice - Hastingwood	0	8	8
Beaumont House Community Hospice - Newark	25	0	25
St Wilfrid's - Chichester	N/A	29	29
St Barnabas Hospices - Worthing	24	17	41
Harris HospisCare - Orpington	25	N/A	25
Great Oaks Dean Forest Hospice - Coleford	21	N/A	21
Manorlands Hospice - Keighley	N/A	30	30
East Cheshire Hospice - Macclesfield	25	15	40
Roxburghe House, Royal Victoria Hospital - Dundee	37	24	61
Greenwich and Bexley Cottage Hospice	26	8	34
Queenscourt Hospice - Southport	14	10	24
Weldmar Hospicecare Trust, Trimar Hospice - Weymouth	24	34	58
Myton Hospices - Warwick	60	2	62
Birmingham St Mary's Hospice	22	12	34
Accord Hospice - Paisley	22	16	38
Weston Hospicecare - Weston-Super-Mare	N/A	19	19
St Clare's Hospice - Jarrow	16	6	22
Mary Stevens Hospice - Stourbridge	32	13	45
Cransley Hospice - Kettering	N/A	44	44
Prospect Hospice - Swindon	23	27	50
Total	1259	963	2222