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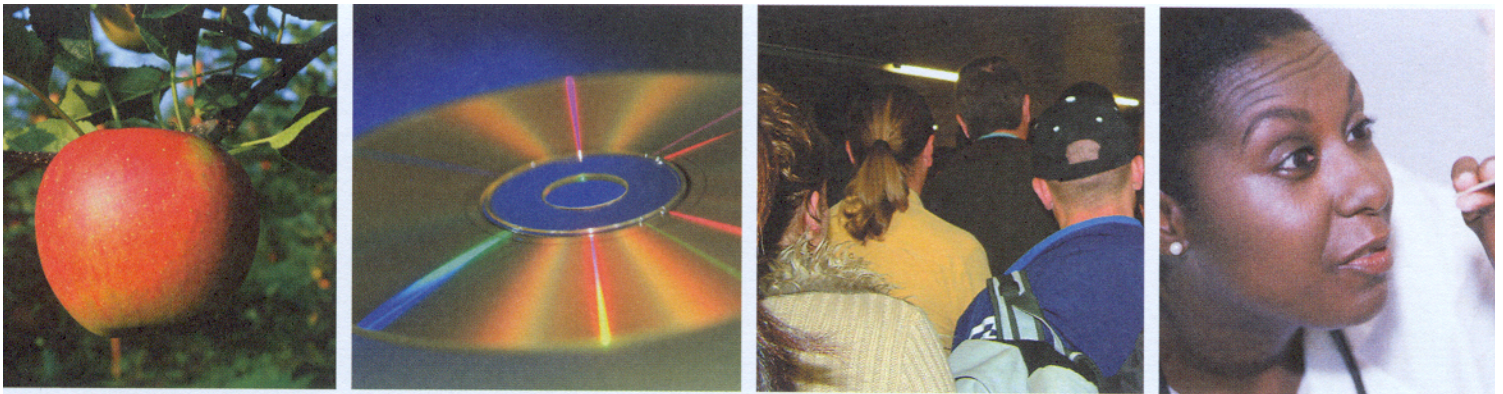
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Results of the 2004/2005 Hospice Patient Survey General Report



Commissioned by: Help the Hospices,
Hospice House, 34-44 Britannia Street. London
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Date: July 2005

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Results of the 2004/2005 Hospice Patient Survey

General Report

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Jan Codling, St Ann's Hospice, Manchester

**Commissioned by:
Nick Pahl, Development Director
Help the Hospices**

Centre for Health Services Studies (CHSS)

The Centre for Health Services Studies (CHSS) is one of three research units in the University of Kent's School of Social Policy, Sociology and Social Research. It contributed to the school's Research Assessment Exercise 5* rating. This put the school in the top three in the UK. CHSS is an applied research unit where research is informed by and ultimately influences practice. The centre has a long history of working with public health practitioners, both as members of staff and as honorary members of staff who are active as consultants to the centre and as practitioners in the field.

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Researchers in the Centre attract funding of nearly £1 million a year from a diverse range of funders including the Economic and Social Research Council, Medical Research Council, Department of Health, NHS Health Trusts and the European Commission.

Funding and acknowledgements

This research was funded by Help the Hospices, Hospice House, 34-44 Britannia Street, London, and by the 53 Hospices who 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 study.

Help the Hospices is the National Charity for the hospice movement.

Contents

| | Pages |
|--|-------|
| Executive Summary | 1 |
| 1.Introduction | 2 |
| 2.Background | 3 |
| 3.Methods | 4 |
| 4. Results: Day-care | 6 |
| 4.1 Individual Hospice Day-care Results (not applicable) | 7 |
| 4.2 Benchmark Day-care Results (13 hospices) | 8 |
| 4.3 Average Day-care Results Overall (50 hospices) | 24 |
| 4.4 Day-care Textual Comments (50 hospices) | 28 |
| 5.Results: In-patient | 32 |
| 5.1 Individual Hospice In-patient Results (not applicable) | 33 |
| 5.2 Benchmark In-patient Results (5 hospices) | 34 |
| 5.3 Average In-patient Results Overall (46 hospices) | 47 |
| 5.4 In-patient Textual comments (46 hospices) | 50 |
| 6.Discussion | 54 |
| 7. Implications for future research | 55 |
| Appendix | |
| A - Day-care questionnaire | |
| B – In-patient questionnaire | |
| C – Questionnaire returns spreadsheet | |

Executive Summary

- The National Minimum Standards for Independent Healthcare, published in 2002 by the Care Standards Commission (now the Healthcare Commission) states that hospices are required to conduct an annual patient survey. In response to this, a Patient Survey group (with representation from independent hospices, Marie Curie Cancer Care and with input from the Care Standards Commission) was set up by Help the Hospices. Its goal was to develop a questionnaire suitable for use in all adult hospices.
- This report details the findings for the 53 Hospices that participated in a patient survey between September 2004 to March 2005. The survey 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 complaints. 1398 questionnaires were returned from day-care patients and 926 from inpatients.
- This report provides individual hospices with their results for day-care and in-patients separately. It also provides benchmark results (includes only those hospices with at least 40 responses), and results for all the participating hospices, both in tabular form and a summary of patients' written comments.
- While results may vary for individual hospices, the benchmark hospices were very similar to the average for all participating hospices.
- Responses from day-care patients and in-patients were quite similar.
- 53% of day-care and 62% of in-patients looked at the information leaflets and nearly all found them easy to understand and helpful. Only 2% of people found incorrect information in them.
- Patients expressed high levels of confidence in the staff, although just under 3% were dissatisfied with their involvement in planning their care. 75% of day-care patients said they always understood explanations about their care, with a slightly smaller percentage of in-patients (68%) saying they always understood explanations. Patients reported high levels of courtesy and efforts to meet their needs.
- Patients expressed high levels of satisfaction with cleanliness (83-88%) and the general environment (84-86%) saying it was excellent. They were also fairly satisfied with the catering (70-75%). The slightly lower satisfaction being expressed by in-patients.
- Day-care patients were asked about transport, and although around three-quarters rated this at the highest level, around 4% said it was 'poor'. They were quite satisfied with the range of available activities (61%). When asked about levels of support when a group member died or was discharged, 7% of day-care patients felt unsupported. 79% said they were always confident that there were enough staff or volunteers around to help if needed.
- In-patients were asked if they had sufficient opportunity to ask questions and make decisions about their care. 78% and 68% respectively said this was always the case. They were nearly all told how to call for assistance and if they did 80% were completely satisfied with the response.
- When asked for their comments on areas where the service could be improved, patients often responded with praise for the service they received, and although some comments were made that hospices can act upon, the great majority of the comments were complimentary. On the whole the comments reiterated the same findings, but they do include a number of specific suggestions.

I. Introduction

The National Minimum Standards for Independent Healthcare, published in 2002 by the Care Standards Commission (now the Healthcare Commission) states that hospices are required to conduct annual patient surveys:

'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' – National Minimum Standards for Independent Healthcare, Standard C6, National Care Standards Commission (NCSC).

In response to this, a Patient Survey group (with representation from independent hospices, Marie Curie Cancer Care and with input from the Care Standards Commission) was set up by Help the Hospices. Its goal was to develop a questionnaire suitable for use in all adult hospices.

The benefits envisaged included prevention of duplication of effort and the opportunity to participate in a national benchmarking scheme.

The resulting questionnaire developed by the group 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 complaints.

Views of patients were sought to ensure clarity and ease of completion prior to finalising the pilot version.

17 Hospices took part in the pilot - circulating anonymised questionnaires with pre paid envelopes to inpatients at discharge or after 2 months of attending day-care between April to September 2003. Changes to the style and content were then made in response to user feedback.

This report details the findings for the 53 Hospices that participated in a patient survey between September 2004 to March 2005.

The questionnaires were returned to and analysed by the Centre for Health Services Research at the University of Kent. The data from hospices, who achieved 40 or more returned questionnaires, has also been analysed in a benchmarking format. This separate benchmarking allows for individual hospices to compare their results against hospices that achieved a higher response, which is more statistically valid.

We hope you find this report useful.

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

Nick Pahl, Development Director, Help the Hospices.

2. Background

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, hospice care has grown into a worldwide movement that has radically changed approaches to death and dying with its desire to transform the experience of dying. It has been regarded by some as one of the greatest social innovations of the last hundred years.¹

Hospice care and the services they provide are²:

- for those whose illness may no longer be curable, mostly cancer but increasingly other life-threatening illnesses.
- enabling patients to achieve the best possible quality of life
- family support and bereavement services
- considering the whole person and offering physical, emotional and spiritual care
- trying to meet the needs of people from all cultures and communities.

Hospice in-patient services and day-care services, which are the focus of this survey, are just two types of service provision available to the public, others include hospital and home care. Admission as an in-patient in a hospice care unit may be required for control of symptoms, respite care, and terminal care for patients who are in the very final stages of their illness. Provision of day-care services enables many patients to continue living at home while having access to hospice facilities. Day-care services may include medical and nursing care, spiritual support, physiotherapy, occupational therapy, complementary therapies, hairdressing, chiropody and beauty treatments as well as varied creative and social activities.³

¹ Hospice information 'www.hospiceinformation.info/whatishospice.asp' 09/06/2005

² 'Hospice and Palliative Care Directory: United Kingdom and Ireland 2005,' published by 'Hospice Information'

³ 'Hospice and Palliative Care Directory: United Kingdom and Ireland 2005,' published by 'Hospice Information'

3.Methods

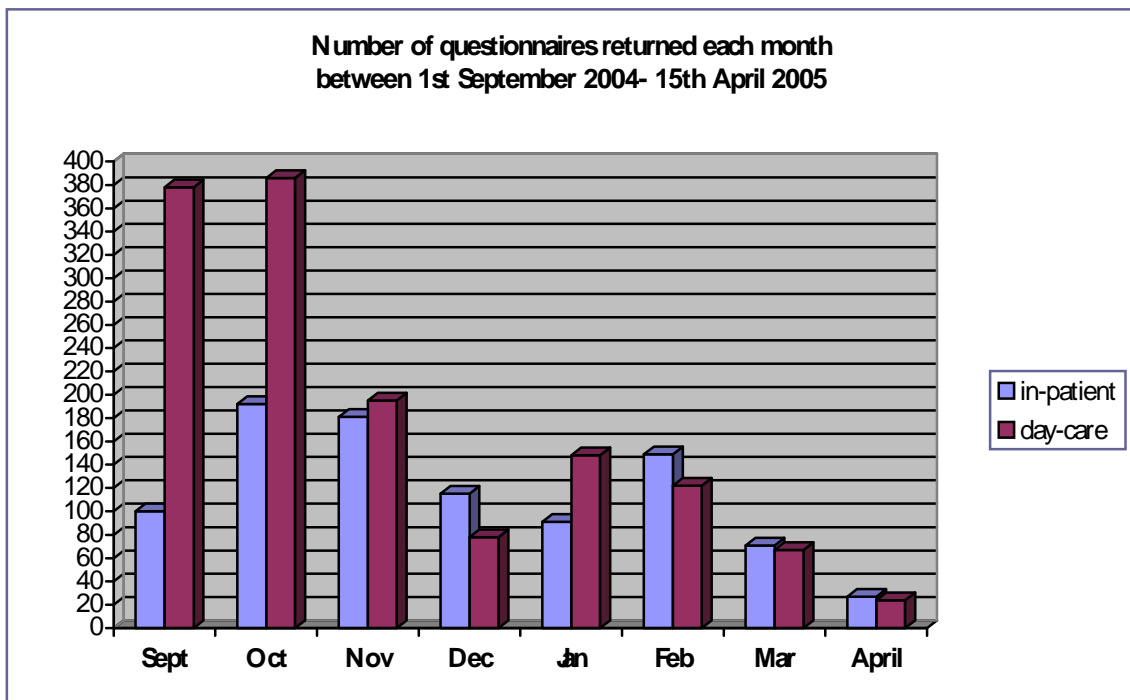
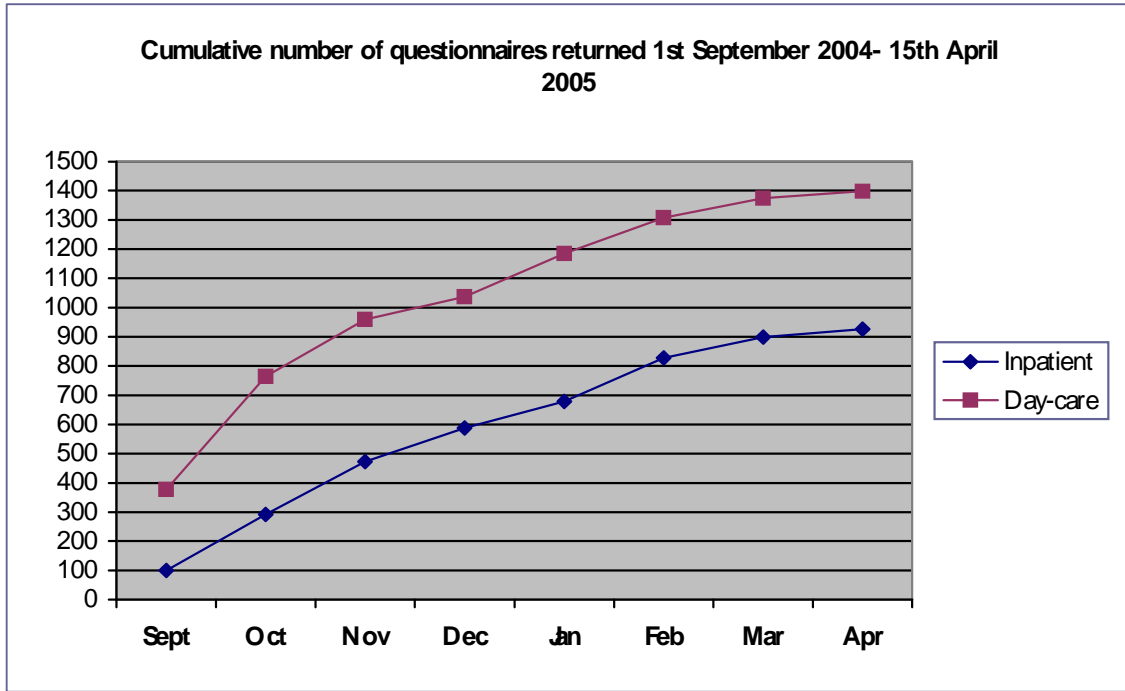
The method of data collection on patient satisfaction with in-patient and day-care services in hospices was by self-completion questionnaire. One questionnaire was designed for the evaluation of day-care services and another for evaluation of in-patient services. A self-completion questionnaire was used as this enabled the collection of a large number of responses at relatively low cost. The content and design of the questionnaires were developed by the Patient Survey Group, a group set up for this purpose, with representation from independent hospices, Marie Curie Cancer Care and with input from the Care Standards Commission. The views of patients were also sought in the development stage of the questionnaires, which helped to ensure clarity and assess the ease of completion. A pilot of the survey was also conducted between April to September 2003 to test the design and content. 17 hospices participated in this pilot, circulating anonymised questionnaires with pre paid envelopes to inpatients at discharge or after 2 months of attending day-care. Changes were then made to according to develop the final survey that was conducted in 2004/05.

Hospices across the UK were invited by letter to take part in the 2004/05 Patient Survey. 53 hospices participated in the survey overall. 43 hospices distributed both day-care services and in-patient services questionnaires, 7 hospices distributed questionnaires to patients using day-care services only, and 3 hospices distributed in-patient services questionnaires only. The survey was distributed only to adult in-patients and day-care units, but there were some other exclusion criteria. Patients with altered consciousness and altered cognitive ability were excluded.

Participating hospices distributed questionnaires to their own patients by printing off electronic copies and distributing them to inpatients at discharge or to day-care patients at discharge or after 2 months of attending. The benefit of individual hospices printing off electronic copies was that hospices could tailor the instructions 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 and with their logo. In order to ensure validity and prevent any bias in the answers given, patients were asked to fill in the questionnaires at home and to return their completed questionnaires in a provided pre-paid envelope addressed to an independent organisation (Centre for Health Services Studies at the University of Kent) who were carrying out the analysis and reporting the survey. 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, 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 is anonymous and the staff giving the care will not see the completed questionnaire and secondly to say that patients were under no pressure to complete the survey and it would have no effect on their future care.

The distribution of questionnaires was originally scheduled for a six month period between September 2004 to February 2005 with a target of 50 completed questionnaires returned from the day-care units and 50 completed questionnaires returned from in-patient units. 50 returns was the number of questionnaires recommended as appropriate for valid benchmarking following the advice of an academic researcher. However it proved difficult to reach this number of returns within this time frame and the data collection period was extended for one further month to the end of March. After the extra month a very small number had reached the benchmark of 50, so after careful consideration it was decided by the research team to drop the benchmark to 40 returns for each service. These experiences may have implications for the how subsequent patients surveys are conducted in future and whether an annual survey is possible.

The tables below show how the questionnaires were returned over the seven-month period. The number of questionnaires returned was much lower for inpatient services (926) compared to day-care services (1398) due to the lower number of patients using these services. Overall the rate in which they were returned was steady for both service types, but returns from day-care units was particularly high at the beginning of data collection during the months of September and October. The high numbers and then the decrease in returns is due to the reducing number of patients who fit the criteria over time. For the actual numbers returned by individual participating hospices see Appendix C.



The collected data was entered and analysed using SPSS v12.01 software (Statistical Package for the Social Sciences). Open ended and textual comments were entered and analysed separately in Excel.

4.Results: Day-care

Results of the survey of day-care patients are given in the following sections:

- 4.1 Individual hospice day-care results
- 4.2 Benchmark day-care results (13 hospices)
- 4.3 Average day-care results overall (50 hospices)
- 4.4 Day-care textual comments (50 hospices)

The Day-care questionnaire is in Appendix A.

4.1 Individual Hospice Day-care Results

(Individual hospice results were included in the reports given to each participating hospice)

4.2 Benchmark Day-care Results (13 hospices)

13 hospices reached the benchmark of 40 returned day-care questionnaires and are included in the benchmark results. This section of the report gives an overview of the average results of these thirteen hospices by presenting the results in tables, charts and a written commentary of the findings for each area covered by the survey: provision of information about services, use of transport, staff communication and care, user involvement and understanding, views of users on support and courtesy of staff, and facilities and services.

The results, in table form, report the average of individuals from all thirteen hospices aggregated together. The range of aggregated results for all 13 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 answer to each question. The average results displayed in these tables are then reported visually in a bar-chart for each question.

Provision of Information about Day-care Services

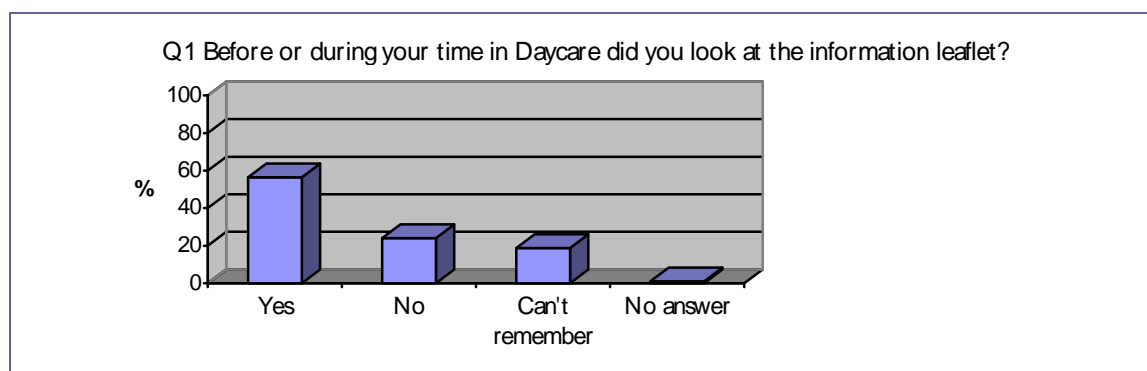
All Day-care patients were asked whether they had looked at the information leaflet on the services that their hospice provides. Some hospices describe these as pamphlets or booklets. If a patient had looked at the leaflet, they were asked some follow up questions about whether they found the leaflet 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.

Just over half (56%) of the day-care patients who responded had looked at the information leaflet, although the results for individual benchmark hospices range between 26-85% clearly showing that day-care patients looking at the information on services available to them varies greatly within different hospices. Therefore it appears that a large proportion of day-care patients may not be seeing or reading the information leaflets provided.

Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on day-care services, with the vast majority of patients who had looked at the leaflet reporting that it was easy to understand (95%) and included information that was helpful to them (93%). All of the patients who had looked at the leaflet described it as being easy to understand and useful in some hospices. Only 2%, equating to 8 patients, said that they found something to be incorrect in the leaflet and only 14% of patients who had looked at the leaflet had made a suggestion for including further or different information (for comments on incorrect leaflets and suggestions of more information see the 4.4 textual comments section of this report).

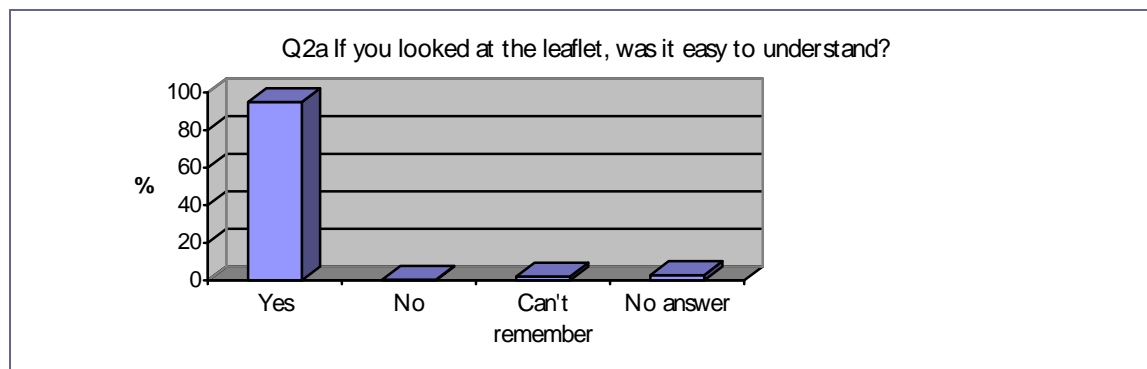
Q1 Before or during your time in Day-care did you look at the information leaflet?

| | N | Average (%) | Range (%) |
|----------------|-----|-------------|-------------|
| Yes | 350 | 56.4 | 26.0 - 85.4 |
| No | 149 | 24 | 7.3 - 42.0 |
| Can't remember | 116 | 18.7 | 7.3 - 34.7 |
| No answer | 6 | 1 | 0 - 2.4 |
| Total | 621 | 100 | |



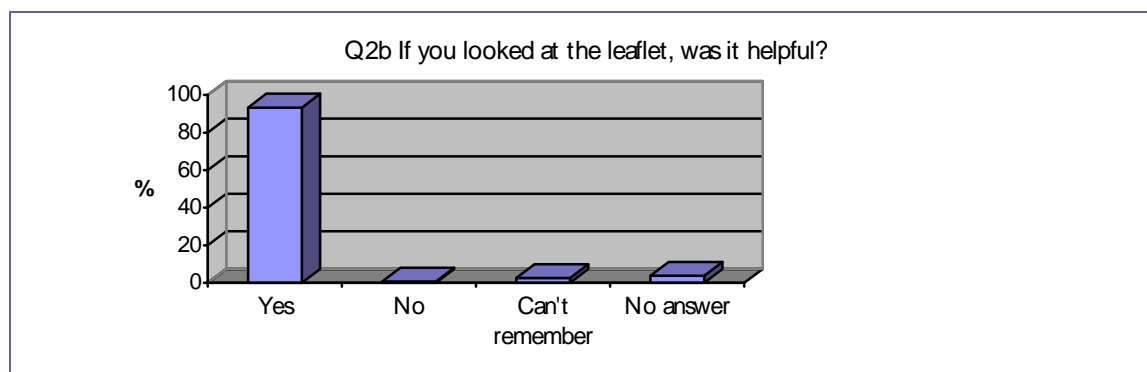
Q2a If you looked at the leaflet was it easy to understand?

| | N | Average (%) | Range (%) |
|---------------------|-----|-------------|------------|
| Yes | 338 | 94.9 | 86.4 - 100 |
| No | 1 | 0.3 | 0 - 3 |
| Can't remember | 7 | 2 | 0 - 6.1 |
| No answer | 10 | 2.8 | 0 - 9.1 |
| Total | 356 | 100 | |
| Not applicable: 265 | | | |



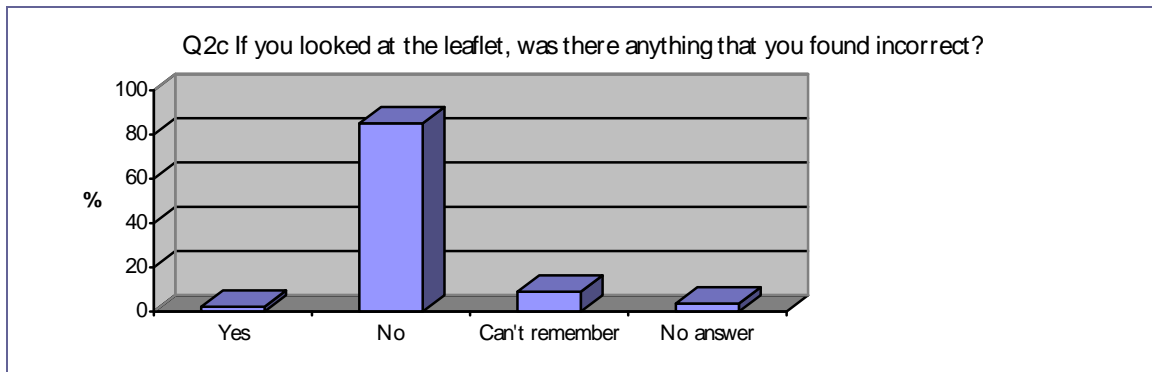
Q2b If you looked at the leaflet was it helpful?

| | N | Average (%) | Range (%) |
|---------------------|-----|-------------|------------|
| Yes | 332 | 93.3 | 84.8 - 100 |
| No | 2 | 0.6 | 0 - 4.3 |
| Can't remember | 9 | 2.5 | 0 - 6.1 |
| No answer | 13 | 3.7 | 0 - 9.1 |
| Total | 356 | 100 | |
| Not applicable: 265 | | | |



Q2c If you looked at the leaflet was there anything that you found incorrect?

| | N | Average (%) | Range (%) |
|---------------------|-----|-------------|-------------|
| Yes | 8 | 2.2 | 0 - 15.4 |
| No | 303 | 85.1 | 53.8 - 95.7 |
| Can't remember | 32 | 9 | 2.2 - 24.1 |
| No answer | 13 | 3.7 | 0 - 9.1 |
| Total | 356 | 100 | |
| Not applicable: 265 | | | |

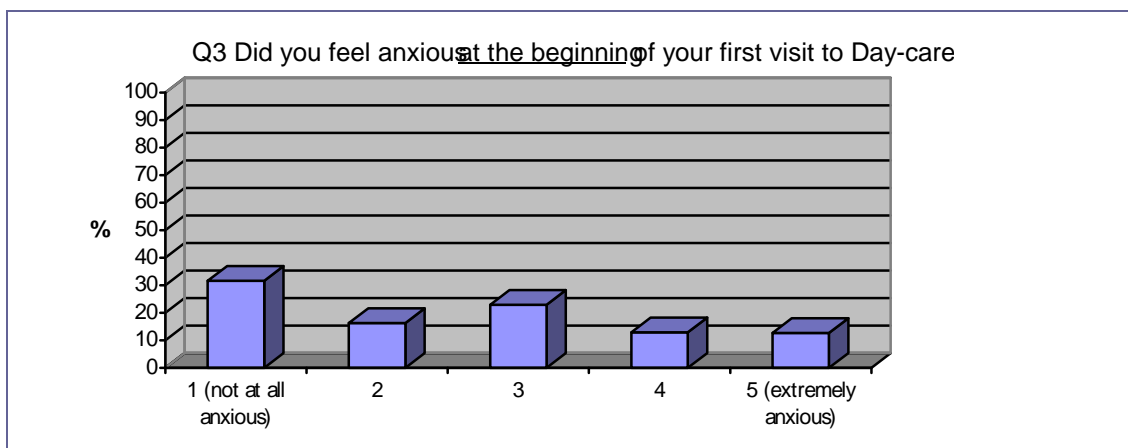


Anxiety on First Day-care Visit

Respondents were asked about how anxious they felt on their first visit to their day-care 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 just under a third (31.6%) of respondents reporting that they were not at all anxious. Answers for 22.9% of the respondents indicated that they felt neither anxious nor not anxious, and 12.7% felt extremely anxious. Respondents were much less anxious at the end of their first visit, with 71.5% reporting that they were not anxious at all, only 2.6% reporting that they felt extremely anxious. When looking more closely at the change in anxiety from the beginning and end of the first visit unsurprisingly the change was towards more respondents becoming less anxious. There was 58.4% change towards people being less anxious at the end of the visit compared to at the beginning, and only a 2.2% change towards being more anxious at the end of the visit compared to the beginning, but these changes were relatively small. There was no change in 39.3% of respondents, and were largely the group who would have felt 'not at all anxious' at the beginning of the visit. Respondents were invited to make suggestions of things the their hospice could have done to relieve their anxiety, These comments are presented in the 4.4 textual comments section of this report.

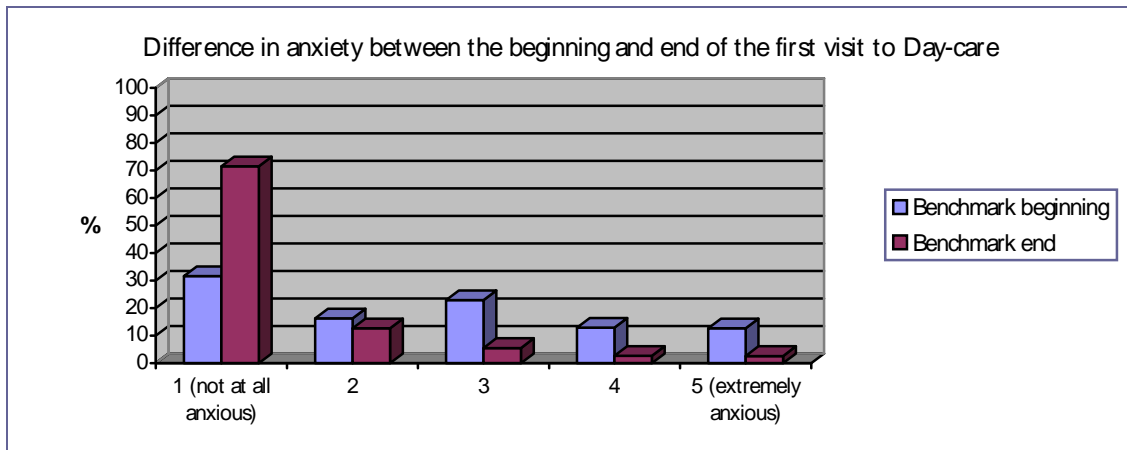
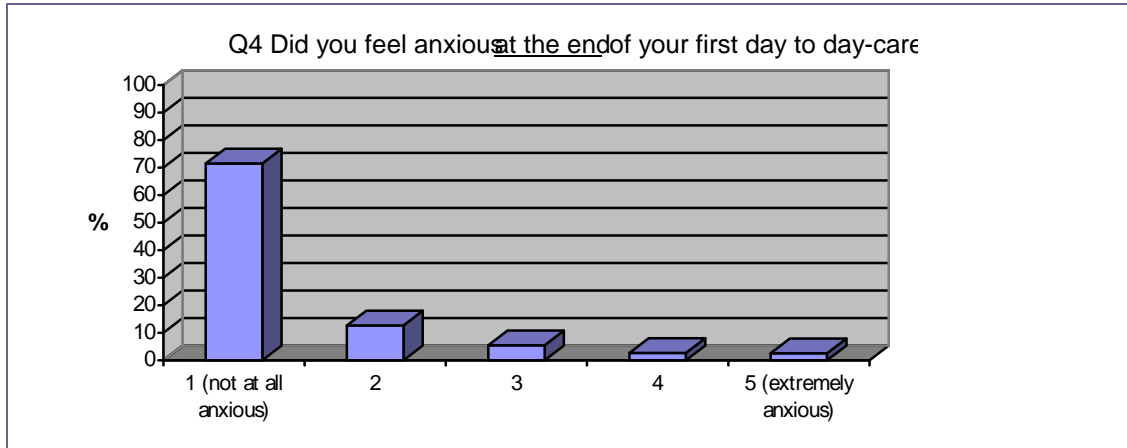
Q3 Did you feel anxious at the beginning of your first visit to Day-care?

| | N | Average (%) | Range (%) |
|-----------------------|-----|-------------|-------------|
| 1. Not at all anxious | 196 | 31.6 | 19.5 – 45.8 |
| 2. | 101 | 16.3 | 8 – 26.8 |
| 3. | 142 | 22.9 | 10.9 – 30.2 |
| 4. | 80 | 12.9 | 6.3 - 22 |
| 5. Extremely anxious | 79 | 12.7 | 4.5 – 19.6 |
| Can't remember | 5 | 0.8 | 0 – 4.5 |
| No answer | 18 | 2.9 | 0 – 6.8 |
| Total | 621 | 100 | |



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

| | N | Average (%) | Range (%) |
|-----------------------|-----|-------------|-------------|
| 1. Not at all anxious | 444 | 71.5 | 55.8 – 82.1 |
| 2. | 79 | 12.7 | 7.3 – 18.6 |
| 3. | 34 | 5.5 | 0 – 10.2 |
| 4. | 17 | 2.7 | 0 – 7.3 |
| 5. Extremely anxious | 16 | 2.6 | 0 – 6.5 |
| Can't remember | 4 | 0.6 | 0 – 3.4 |
| No answer | 27 | 4.3 | 0 – 9.3 |
| Total | 621 | 100 | |



Change in anxiety between the beginning and end of the first visit to Day-care (Q3/4)?

| | N | Average (%) | Range (%) |
|--------------------|-----|-------------|-------------|
| Less anxious | 340 | 58.4 | 46.7 – 81.1 |
| No change | 229 | 39.3 | 16.2 – 53.3 |
| More anxious | 13 | 2.2 | 0 – 5.3 |
| Not applicable: 39 | | | |

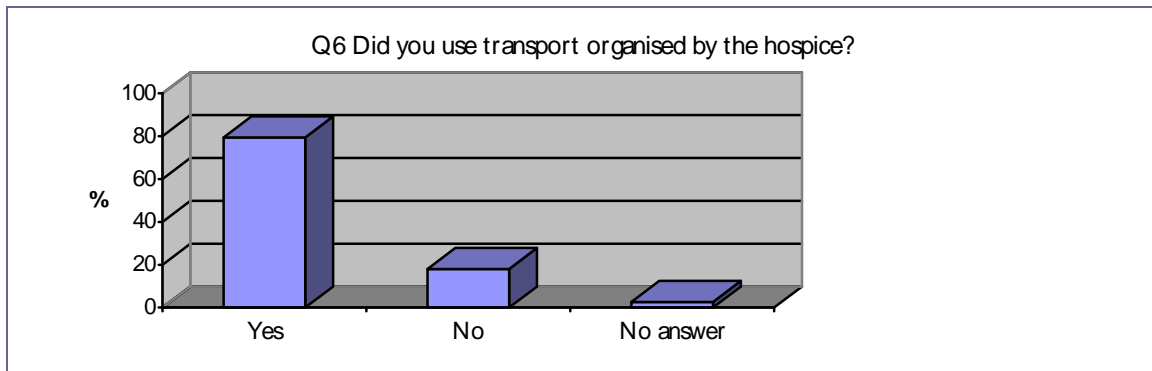
Use of Transport by Day-care Patients

The majority of day-care patients overall (79.4%) and in the hospices individually (range: 58.5% - 95.8) have used transport organised by their hospice. The majority who reported using transport organised by their hospice also reported the standard of this service to be excellent. 75.8% of those who had used the

transport felt the promptness of pick up was excellent compared to 5.7 who felt it was poor. Similarly, 73.7% felt the comfort of the journey was excellent compared to 5.7 who felt it was poor and 78.8% felt the safety aspects were excellent compared to 5.5% who felt it was poor. The ranges reported below show that there was some variation in these views but again 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.

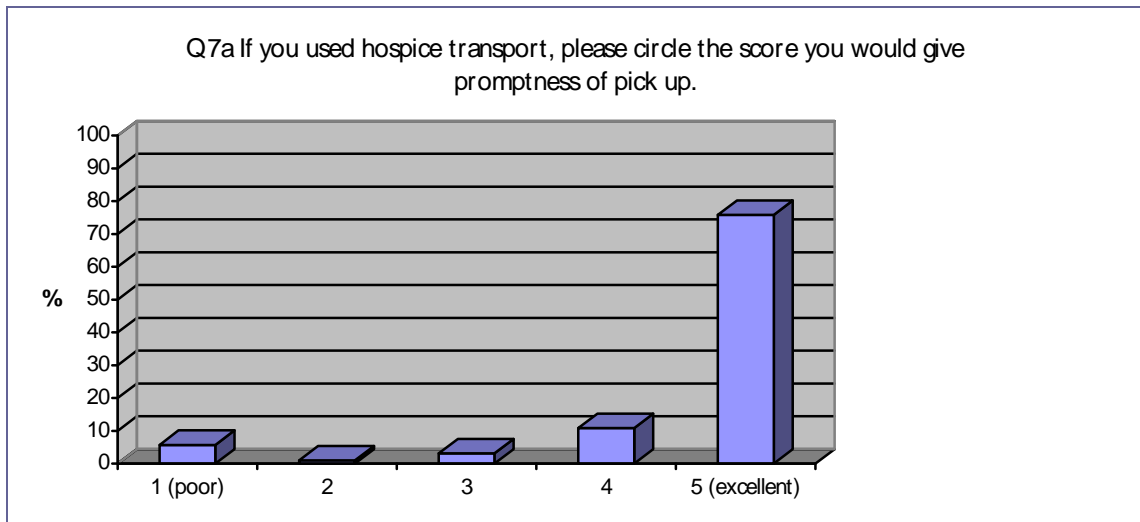
Q6 Did you use transport organised by the hospice?

| | N | Average (%) | Range (%) |
|-----------|-----|-------------|-------------|
| Yes | 493 | 79.4 | 58.5 - 95.8 |
| No | 112 | 18 | 2.1- 41.5 |
| No answer | 16 | 2.6 | 0 - 10 |
| Total | 621 | 100 | |



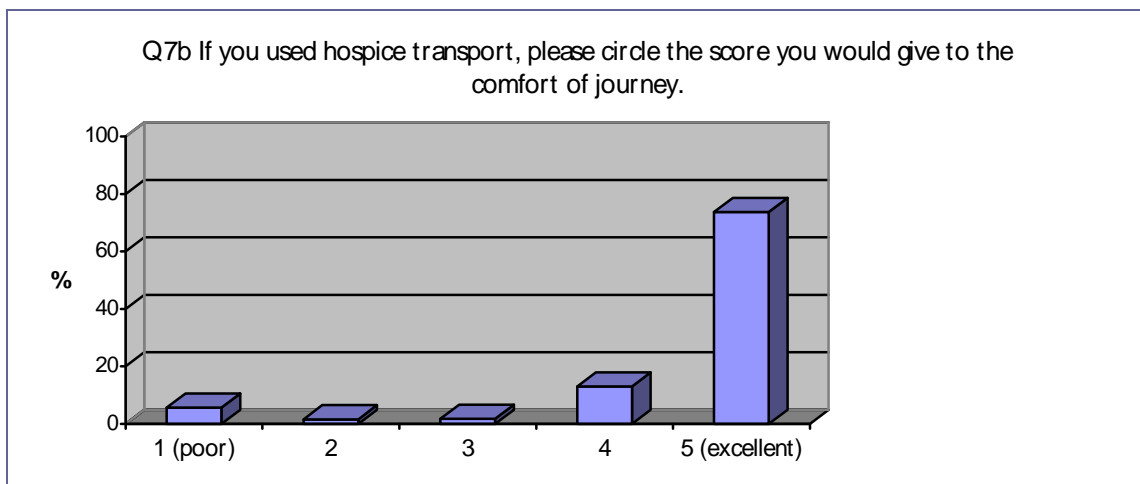
Q7a If you used hospice transport, please circle the score you would give promptness of pickup

| | N | Average (%) | Range (%) |
|---------------------|-----|-------------|-------------|
| 1. Poor | 29 | 5.7 | 2.2 – 10.5 |
| 2. | 5 | 1.0 | 0 – 7.9 |
| 3. | 16 | 3.1 | 0 – 13.2 |
| 4. | 55 | 10.8 | 2.2 – 21.1 |
| 5. Excellent | 386 | 75.8 | 55.3 – 90.5 |
| No answer | 18 | 3.5 | 0 – 10.3 |
| Total | 509 | 100 | |
| Not applicable: 112 | | | |



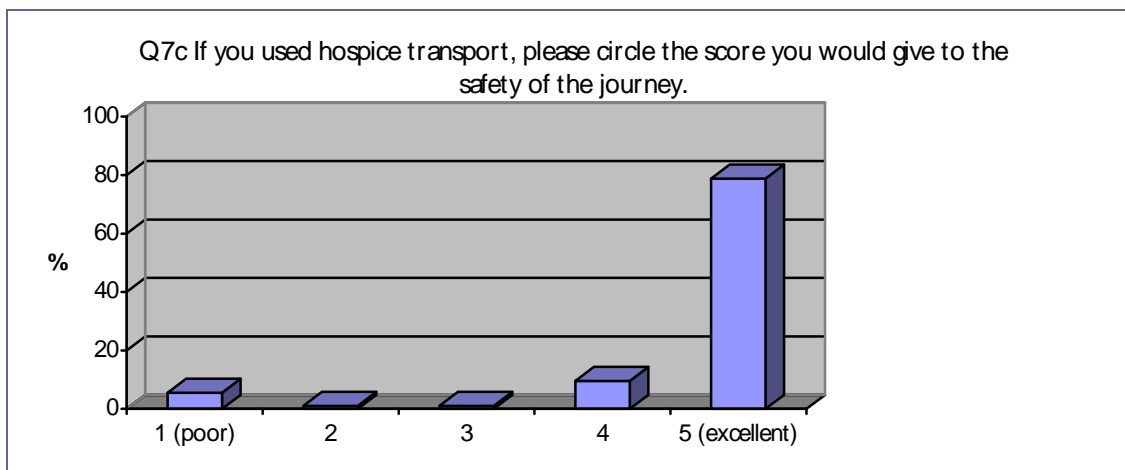
Q7b If you used hospice transport, please circle the score you would give to the comfort of journey

| | N | Average (%) | Range (%) |
|---------------------|-----|-------------|-------------|
| 1. Poor | 29 | 5.7 | 2.4 - 10 |
| 2. | 8 | 1.6 | 0 - 5.4 |
| 3. | 9 | 1.8 | 0 - 7.9 |
| 4. | 66 | 13 | 7 - 21.1 |
| 5. Excellent | 375 | 73.7 | 51.3 - 87.5 |
| No answer | 22 | 4.3 | 0 - 12.8 |
| Total | 509 | 100 | |
| Not applicable: 112 | | | |



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

| | N | Average (%) | Range (%) |
|---------------------|-----|-------------|-------------|
| 1. Poor | 28 | 5.5 | 2.4 - 10 |
| 2. | 5 | 1 | 0 - 5.3 |
| 3. | 5 | 1 | 0 - 7.9 |
| 4. | 49 | 9.6 | 1.8 - 20 |
| 5. Excellent | 401 | 78.8 | 64.1 - 91.7 |
| No answer | 21 | 4.1 | 0 - 12.8 |
| Total | 509 | 100 | |
| Not applicable: 112 | | | |



Day-care Staff Communication and Care

The survey asked respondents about the communication and care they had received from staff in Day-care. The majority (79.2%) of respondents reported that staff involved in their care always introduced themselves when they used the day-care services. A further 16.1% said they introduced themselves most of the time and only one respondent said that staff had never introduced themselves. As well as an introduction staff were also frequently explaining to the patient what they were doing when caring for them. 71.8% reported that staff always explained what they were doing, 21.9% reported most of the time, and only 3 respondents reported that staff had never explained what they were doing. Respondents using day-care services were also asked whether they had confidence in the staff who were caring for them overall. Again the response was very positive with 90.2% reporting this always to be the case. 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.

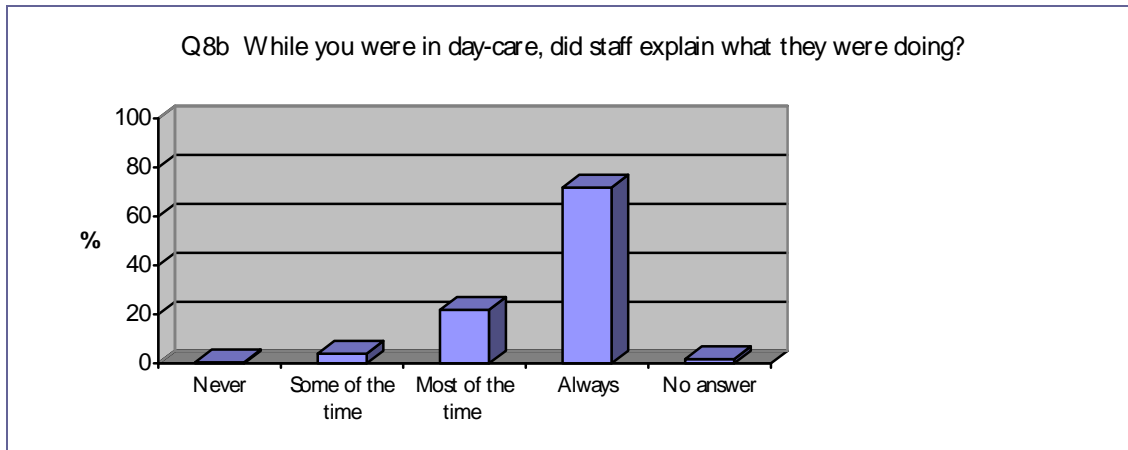
Q8a. While you were in day-care, did staff involved in your care introduce themselves?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|------------|
| Never | 1 | 0.2 | 0 – 2.3 |
| Some of the time | 10 | 1.6 | 0 – 8.3 |
| Most of the time | 100 | 16.1 | 5.6 – 34.1 |
| Always | 492 | 79.2 | 56.1 – 87 |
| No answer | 18 | 2.9 | 0 – 7.3 |
| Total | 621 | 100 | |



Q8b. While you were in day-care, did staff explain what they were doing?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 3 | 0.5 | 0 – 4.5 |
| Some of the time | 25 | 4 | 0 – 11.4 |
| Most of the time | 136 | 21.9 | 12.2 – 32.7 |
| Always | 446 | 71.8 | 52.3 – 85.4 |
| No answer | 11 | 1.8 | 0 – 5.1 |
| Total | 621 | 100 | |



Q9. Overall did you have confidence in the staff who were caring for you?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 2 | 0.3 | 0 – 2 |
| Some of the time | 2 | 0.3 | 0 – 2.4 |
| Most of the time | 45 | 7.2 | 0 – 15.2 |
| Always | 560 | 90.2 | 81.4 – 97.7 |
| No answer | 12 | 1.9 | 0 – 4.7 |
| Total | 621 | 100 | |



Day-care User Involvement and Understanding

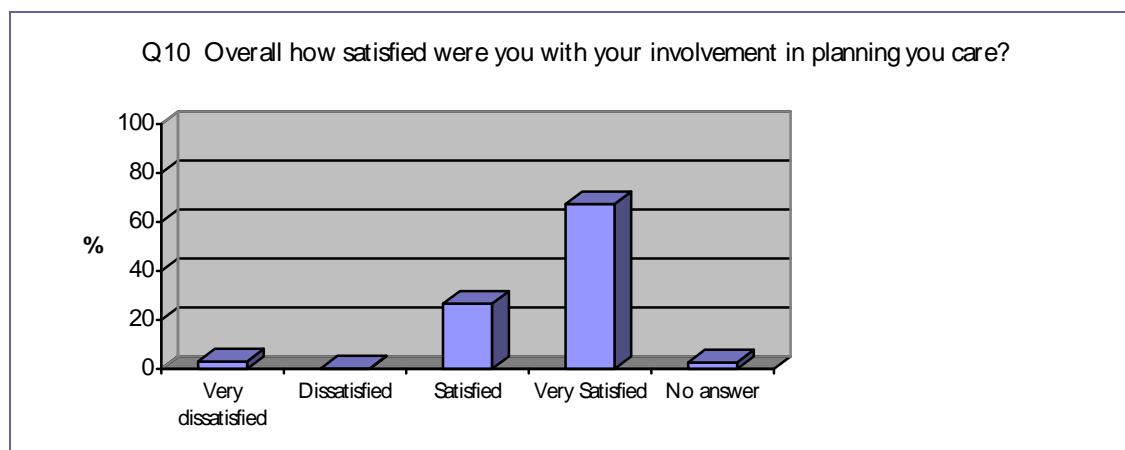
Respondents were asked about their overall satisfaction with their involvement in the planning of their care while in day-care. Just over two thirds (67.3%) were very satisfied, and 26.7% were satisfied with the level of involvement in their care. Curiously more respondents felt they were very dissatisfied compared to just feeling dissatisfied. However the proportion that were either dissatisfied or very dissatisfied was very small. Of those who were either dissatisfied or very dissatisfied only 3 respondents made suggestions

as to how their hospice could involve them more (for these suggestions of more information see the 4.4 textual comments sections of this report).

The survey also asked about users understanding of the explanations given to them about their care whilst in day-care. It is encouraging that the majority (76%) felt that they always understood the explanations given, and 15.6 said they understood most of the time. Only 7.6% of respondents suggested ways of making their hospice's explanations clearer. (for suggestions see the 4.4 textual comments sections of this report).

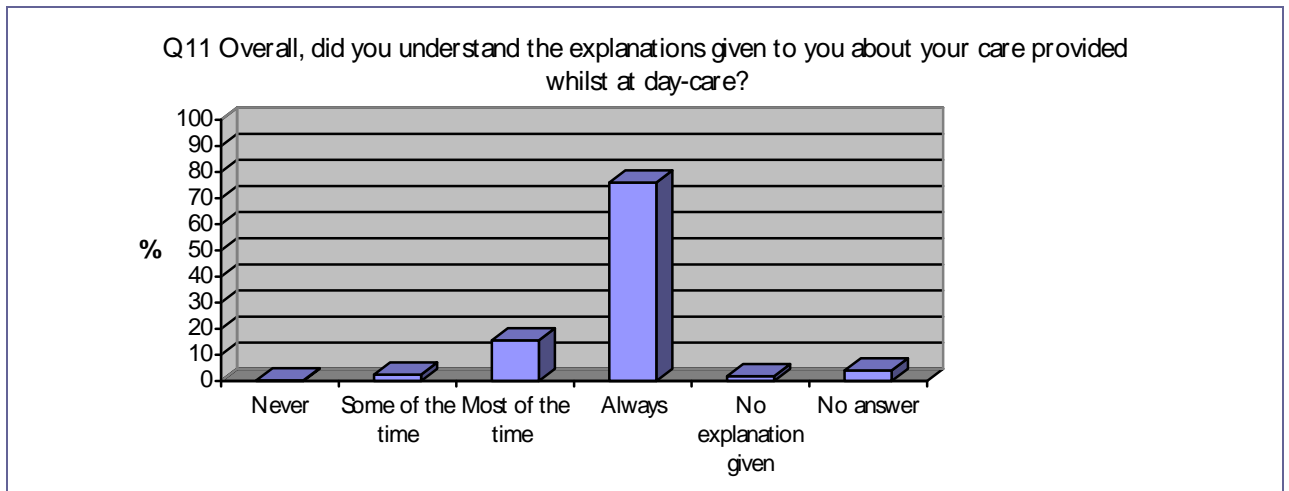
Q10 Overall how satisfied were you with your involvement in planning your care?

| | N | Average (%) | Range (%) |
|-------------------|-----|-------------|-------------|
| Very dissatisfied | 19 | 3.1 | 0 – 9.8 |
| Dissatisfied | 1 | 0.2 | 0 – 2.4 |
| Satisfied | 166 | 26.7 | 8.7 – 68.2 |
| Very Satisfied | 418 | 67.3 | 22.7 – 89.1 |
| No answer | 17 | 2.7 | 0 – 9.3 |
| Total | 621 | 100 | |



Q11 Overall, did you understand the explanations given to you about your care provided while at Day-care (this does not include the care provided by your GP or hospital)?

| | N | Average (%) | Range (%) |
|----------------------|-----|-------------|-------------|
| Never | 1 | 0.2 | 0 – 2.3 |
| Some of the time | 15 | 2.4 | 0 – 6.1 |
| Most of the time | 97 | 15.6 | 7.3 – 22.7 |
| Always | 472 | 76 | 69.4 – 87.8 |
| No explanation given | 11 | 1.8 | 0 – 6.8 |
| No answer | 25 | 4 | 0 – 7 |
| Total | 621 | 100 | |



Views of Users on the Support and Courtesy of Day-care Staff

A number of questions were asked in the survey about patient views on the support and courtesy of the staff looking after them in day-care. Just over half the respondents (52%) felt extremely supported when a group member had been discharged or died, compared to only 3.9% who felt totally unsupported. The proportion of those saying they were extremely supported is particularly variable for the benchmark hospices individually (range: 34.4% – 73%). More generally, respondents were very positive in the support they received from staff. 76.7% of respondent's felt that they were always given the opportunity to ask questions when they want to, and 79.1% felt that staff always made an effort to meet their individual needs and wishes. 14.8% felt that staff offered support in both of these ways most of the time. Approximately 9 in every 10 felt that staff were always courteous and respected their privacy: 93.4% felt they were always treated with courtesy and 89% felt that their privacy was always respected, for example when being examined or during discussions with staff. Only 4 respondents felt that their privacy was never respected.

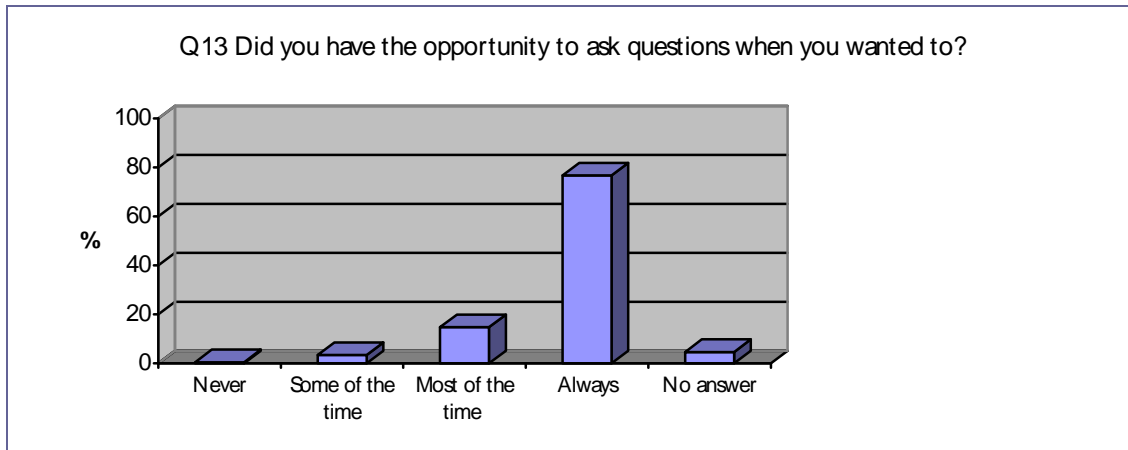
Q12 How supported did you feel when a group member was discharged or died?

| | N | Average (%) | Range (%) |
|---|-----|-------------|-------------|
| 1. Totally unsupported | 17 | 3.9 | 0 – 15.6 |
| 2. | 17 | 3.9 | 0 – 17.4 |
| 3. | 53 | 12.2 | 3.1 – 22.6 |
| 4. | 90 | 20.7 | 10.8 – 31.6 |
| 5. Extremely supported | 226 | 52 | 34.4 - 73 |
| No answer | 32 | 7.4 | 0 - 13 |
| Total | 435 | 100 | |
| Not applicable as no one has died or been discharged: 186 | | | |



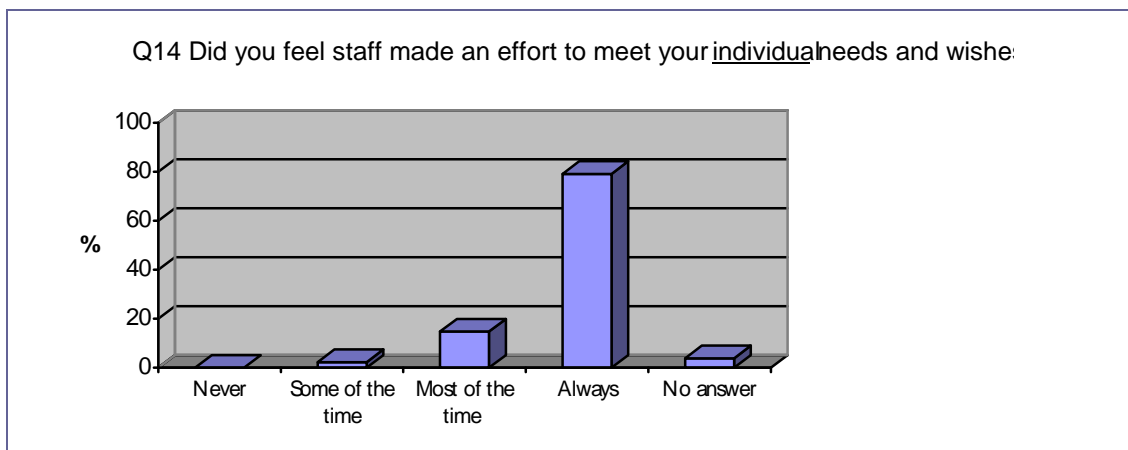
Q13 Did you have the opportunity to ask questions when you wanted to?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 3 | 0.5 | 0 – 2.4 |
| Some of the time | 21 | 3.4 | 0 – 9.1 |
| Most of the time | 92 | 14.8 | 4.9 – 20.9 |
| Always | 476 | 76.7 | 61.4 – 86.4 |
| No answer | 29 | 4.7 | 0 – 10.2 |
| Total | 621 | 100 | |



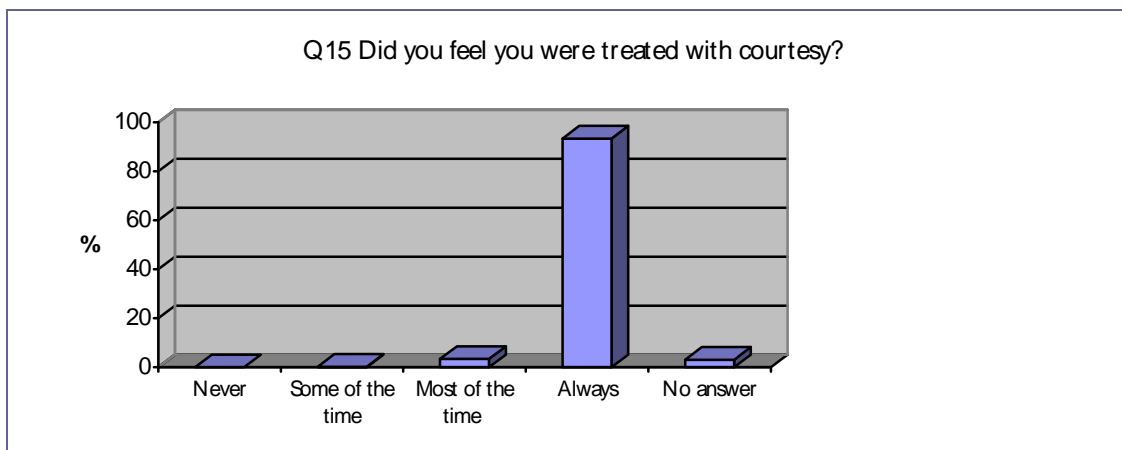
Q14 Did you feel staff made an effort to meet your individual needs and wishes?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 - 0 |
| Some of the time | 14 | 2.3 | 0 – 11.9 |
| Most of the time | 92 | 14.8 | 9.1 – 20.8 |
| Always | 491 | 79.1 | 64.6 – 90.2 |
| No answer | 24 | 3.9 | 0 – 10.2 |
| Total | 621 | 100 | |



Q15 Did you feel you were treated with courtesy?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 1 | 0.2 | 0 – 2.1 |
| Most of the time | 21 | 3.4 | 0 – 10.4 |
| Always | 580 | 93.4 | 81.3 – 100 |
| No answer | 19 | 3.1 | 0 - 7 |
| Total | 621 | 100 | |



Q16 Did you feel your privacy was respected e.g. when being examined or during discussions with staff?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 4 | 0.6 | 0 – 4.3 |
| Some of the time | 3 | 0.5 | 0 – 4.2 |
| Most of the time | 34 | 5.5 | 1.9 – 13.6 |
| Always | 554 | 89.2 | 79.2 – 95.1 |
| No answer | 26 | 4.2 | 0 – 9.3 |
| Total | 621 | 100 | |



Day-care Facilities and Services

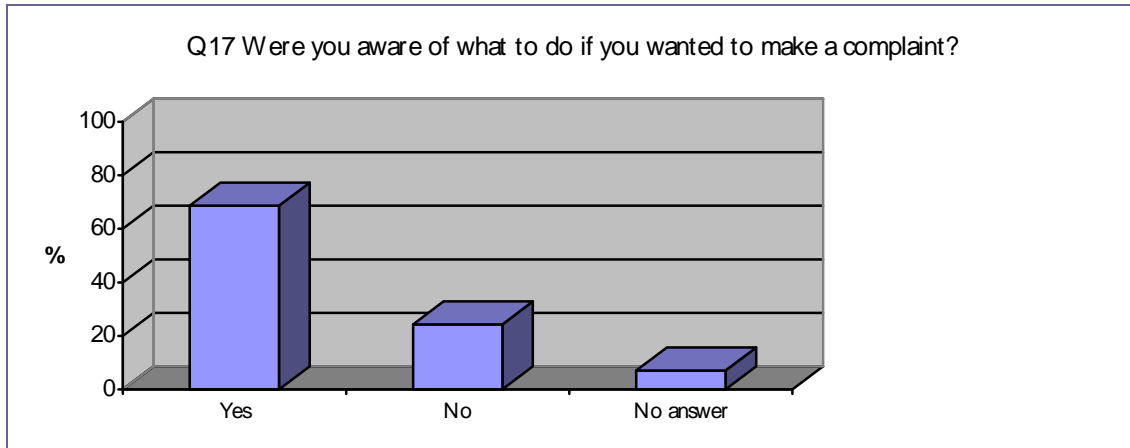
The type of facilities and services offered in day-care can vary greatly. This survey concentrated on general questions about facilities and services which would be applicable to all hospices. It asked about awareness of facilities available to make a complaint, what they thought about the quality of the catering, the activities available, the number of staff and volunteers available when needed, and also views on the day-care building itself by asking questions about the general environment/surroundings and the cleanliness of the premises.

Just over two thirds of respondents (68.6%) were aware of how to make a complaint compared to 24.3% who were not. However the awareness did vary between the benchmark hospices (those aware ranged between 45.5% - 88.1%). When asked to rate the following facilities and services they were viewed by the majority to be of a high standard and rated as excellent: the cleanliness of the premises (88.9%), the quality of the catering (76.2%), the activities available to participate in (65.7%) and the general environment and surroundings (86.3%). Only between 1-2% felt that any of these facilities or services were poor. The quality of the catering and the activities available were the most variable among the different benchmark hospices. Respondents were invited to make further comments on these facilities

and services which can be found in the 4.4 textual comments section of this report. Regarding the number of staff and volunteers working in the respondent's hospice, the majority (81.5%) felt confident that there were enough around to offer help if needed, and 15% felt that there were enough most of the time.

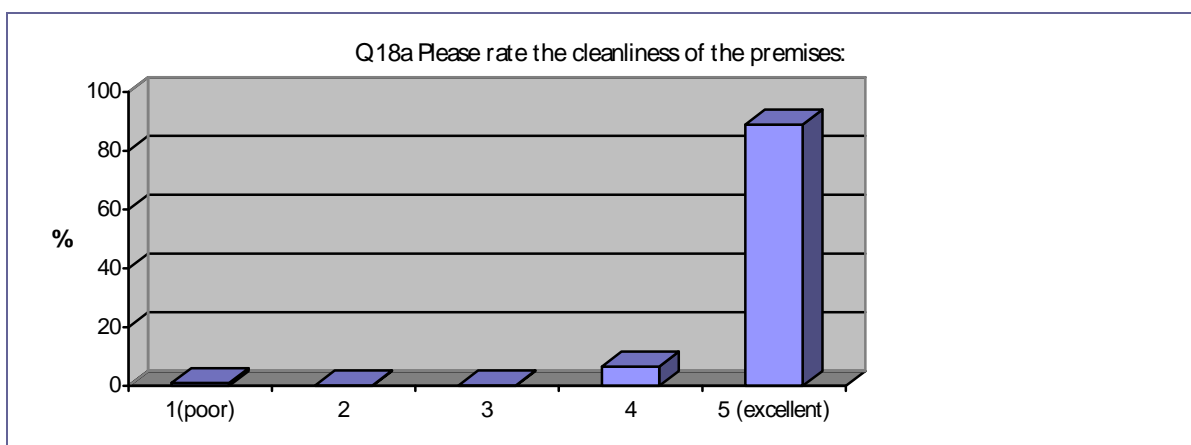
Q17 Were you aware of what to do if you wanted to make a complaint?

| | N | Average (%) | Range (%) |
|-----------|-----|-------------|-------------|
| Yes | 426 | 68.6 | 45.5 – 88.1 |
| No | 151 | 24.3 | 5.1 – 44 |
| No answer | 44 | 7.1 | 0 - 14 |
| Total | 621 | 100 | |



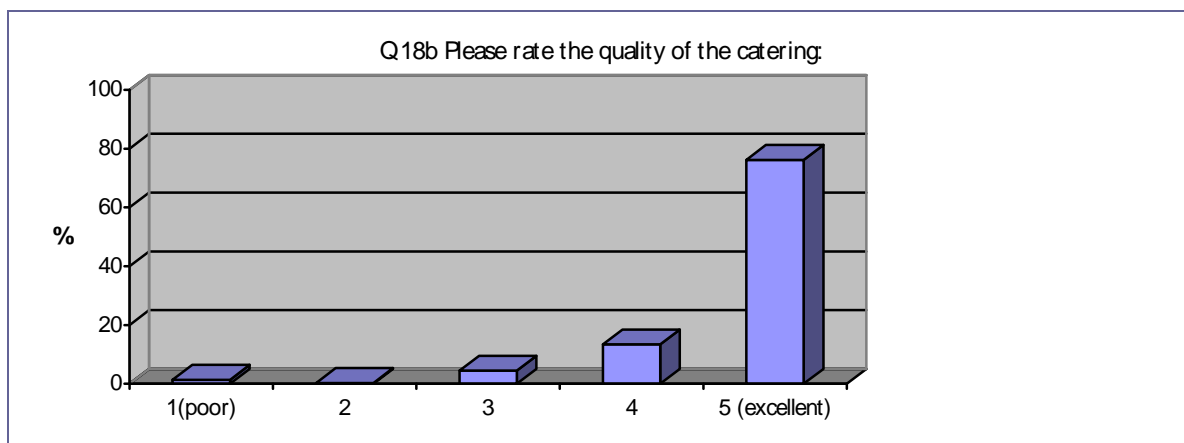
Q18a Please rate the cleanliness of the premises:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|------------|
| 1. Poor | 6 | 1 | 0 – 3.4 |
| 2. | 1 | 0.2 | 0 – 2 |
| 3. | 1 | 0.2 | 0 – 2.2 |
| 4. | 41 | 6.6 | 0 – 9.8 |
| 5. Excellent | 552 | 88.9 | 83.7 - 100 |
| No answer | 20 | 3.2 | 0 –7 |
| Total | 621 | 100 | |



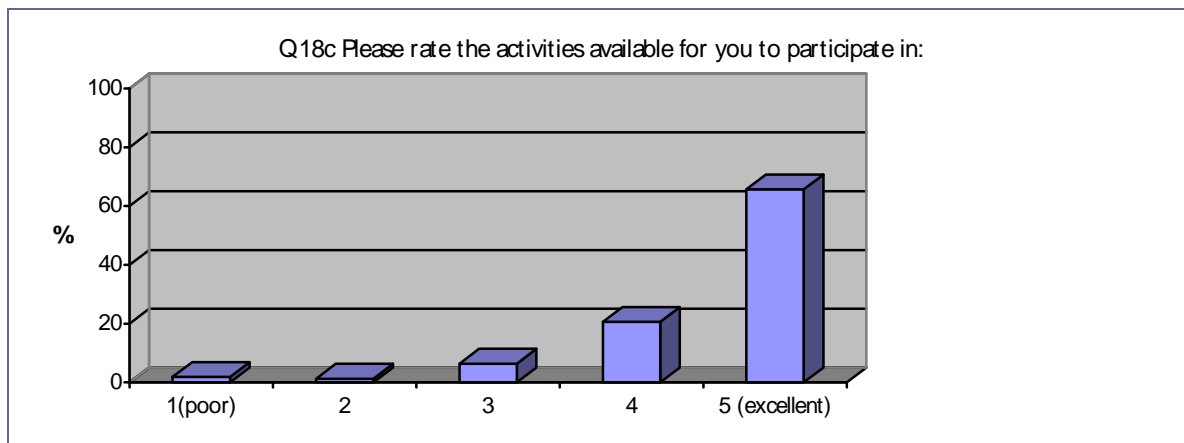
Q18b Please rate the quality of the catering:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|-------------|
| 1. Poor | 9 | 1.4 | 0 – 6.1 |
| 2. | 2 | 0.3 | 0 – 4.5 |
| 3. | 28 | 4.5 | 0 – 14.6 |
| 4. | 83 | 13.4 | 4.9 - 24 |
| 5. Excellent | 473 | 76.2 | 57.6 – 95.1 |
| No answer | 26 | 4.2 | 0 – 10.9 |
| Total | 621 | 100 | |



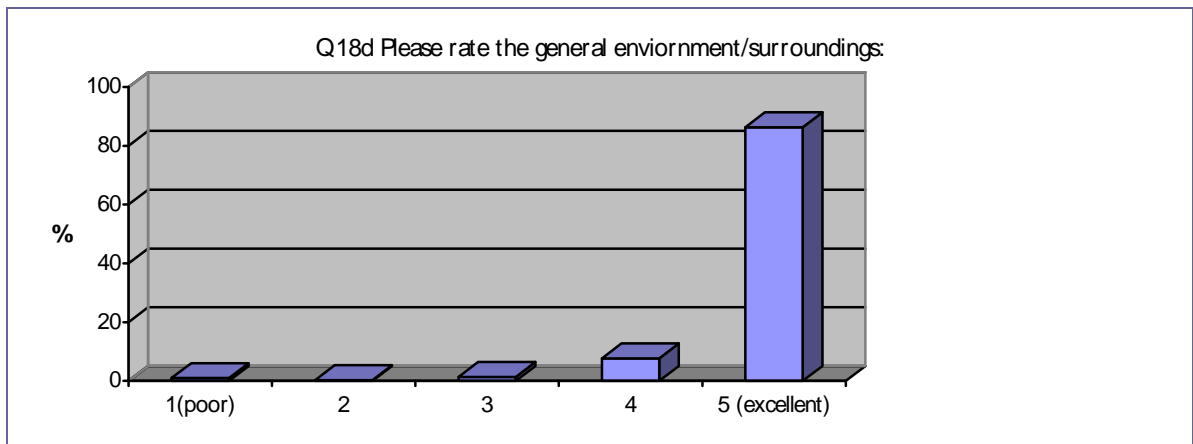
Q18c Please rate the activities available for you to participate in:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|-------------|
| 1. Poor | 12 | 1.9 | 0 – 6.1 |
| 2. | 8 | 1.3 | 0 – 6 |
| 3. | 40 | 6.4 | 0 – 28 |
| 4. | 128 | 20.6 | 11.1 – 38.6 |
| 5. Excellent | 408 | 65.7 | 31.8 – 80.5 |
| No answer | 25 | 4 | 0 – 9.1 |
| Total | 621 | 100 | |



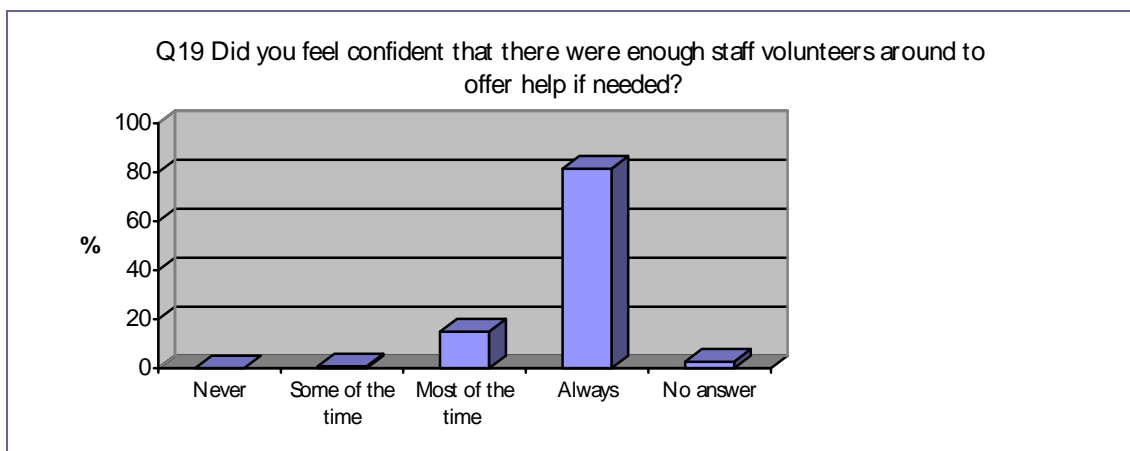
Q18d Please rate the general environment/surroundings:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|-------------|
| 1. Poor | 6 | 1 | 0 – 3.4 |
| 2. | 2 | 0.3 | 0 – 2 |
| 3. | 9 | 1.4 | 0- 4.5 |
| 4. | 48 | 7.7 | 2.2 – 14.3 |
| 5. Excellent | 536 | 86.3 | 78.3 – 97.6 |
| No answer | 20 | 3.2 | 0 - 7 |
| Total | 621 | 100 | |



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

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 5 | 0.8 | 0 – 2.4 |
| Most of the time | 93 | 15 | 4.3 – 26.8 |
| Always | 506 | 81.5 | 70.7 – 94 |
| No answer | 17 | 2.7 | 0 – 6.5 |
| Total | 621 | 100 | |



4.3 Average Day-care Results Overall (50 Hospices)

The following results report the average of individuals aggregated together from all 50 hospices who took part in the day-care questionnaire. The total number of returned questions received from day-care patients was 1398.

Service: Day-care
N: 1398

Q1 Before or during your time in Day-care did you look at the information leaflet?

| Yes: | No | Can't remember | No answer |
|-------------|-------------|----------------|-----------|
| 745 (53.3%) | 400 (28.6%) | 237 (17%) | 16 (1.1%) |

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

| Yes | No | Can't remember | No answer |
|---------------------|----------|----------------|-----------|
| 715 (94%) | 2 (0.3%) | 20 (2.6%) | 24 (3.2%) |
| Not applicable: 637 | | | |

Q2b If you looked at the leaflet was it helpful?

| Yes | No | Can't remember | No answer |
|---------------------|----------|----------------|-----------|
| 706 (92.8%) | 2 (0.3%) | 21 (2.8%) | 32 (4.2%) |
| Not applicable: 637 | | | |

Q2c If you looked at the leaflet was there anything that you found incorrect?

| Yes | No | Can't remember | No answer |
|---------------------|-------------|----------------|-----------|
| 14 (1.8%) | 649 (85.3%) | 67 (8.8%) | 31 (4.1%) |
| Not applicable: 637 | | | |

Q3 Did you feel anxious at the beginning of your first visit to Day-care?

| I =Not at all anxious → 5 =Extremely anxious | | | | | Can't remember | No answer |
|--|-------------|-------------|-------------|-------------|----------------|-----------|
| 1 | 2 | 3 | 4 | 5 | | |
| 408 (29.2%) | 213 (15.2%) | 360 (25.8%) | 175 (12.5%) | 175 (12.5%) | 17 (1.2%) | 50 (3.6%) |

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

| I =Not at all anxious → 5 =Extremely anxious | | | | | Can't remember | No answer |
|--|-------------|-----------|-----------|-----------|----------------|-----------|
| 1 | 2 | 3 | 4 | 5 | | |
| 979 (70%) | 180 (12.9%) | 87 (6.2%) | 41 (2.9%) | 36 (2.6%) | 16 (1.1%) | 59 (4.2%) |

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

| Less anxious | No change | More anxious |
|--------------------|-------------|--------------|
| 788 (60.3%) | 478 (36.6%) | 40 (3.1%) |
| Not applicable: 92 | | |

Q6 Did you use transport organised by the hospice?

| Yes | No | No answer |
|------------|-------------|-----------|
| 1007 (72%) | 355 (25.4%) | 36 (2.6%) |

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 | |
| Promptness of Pick up | 44 (4.2%) | 11 (1.1%) | 40 (3.8%) | 123 (11.8%) | 772 (74%) | 53 (5.1%) |
| Comfort of the journey | 42 (4%) | 19 (1.8%) | 33 (3.2%) | 125 (12%) | 764 (73.3%) | 60 (5.8%) |
| Safety of the journey | 41 (3.9%) | 9 (0.9%) | 14 (1.3%) | 94 (9.0%) | 829 (79.5%) | 56 (5.4%) |
| Not applicable: 355 | | | | | | |

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

| Never | Some of the time | Most of the time | Always | No answer |
|----------|------------------|------------------|--------------|-----------|
| 2 (0.1%) | 25 (1.8%) | 201 (14.4%) | 1123 (80.3%) | 47 (3.4%) |

Q8b While you were in Day-care did staff explain what they were doing?

| Never | Some of the time | Most of the time | Always | No answer |
|----------|------------------|------------------|--------------|-----------|
| 4 (0.3%) | 55 (3.9%) | 286 (20.5%) | 1018 (72.8%) | 35 (2.5%) |

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

| Never | Some of the time | Most of the time | Always | No answer |
|----------|------------------|------------------|--------------|-----------|
| 3 (0.2%) | 4 (0.3%) | 100 (7.2%) | 1261 (90.2%) | 30 (2.1%) |

Q10 Overall how satisfied were you with your involvement in planning your care?

| Very dissatisfied | Dissatisfied | Satisfied | Very satisfied | No answer |
|-------------------|--------------|-----------|----------------|-----------|
| 34 (2.4%) | 5 (0.4%) | 364 (26%) | 955 (68.3%) | 40 (2.9%) |

Q11 Overall, did you understand the explanations given to you about your care provided whilst at Day-care (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 |
|----------|------------------|------------------|--------------|----------------------|-----------|
| 1 (0.1%) | 33 (2.4%) | 246 (17.6%) | 1044 (74.7%) | 19 (1.4%) | 55 (3.9%) |

Q12 How supported did you feel when a group member was discharged or died?

| 1 =totally unsupported supported —————> 5 =Extremely supported | | | | | No answer |
|--|--------------|----------------|----------------|----------------|--------------|
| 1 | 2 | 3 | 4 | 5 | |
| 32 (3.4%) | 34 (3.6%) | 133 (14.1%) | 193 (20.5%) | 474 (50.3%) | 77 (8.2%) |
| Not applicable as no one has died or been discharged: 455 | | | | | |

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 |
|----------|------------------|------------------|--------------|-----------|
| 7 (0.5%) | 41 (2.9%) | 214 (15.3%) | 1068 (76.4%) | 68 (4.9%) |

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 |
|----------|------------------|------------------|--------------|-----------|
| 3 (0.2%) | 28 (2%) | 230 (16.5%) | 1082 (77.4%) | 55 (3.9%) |

Q15 Did you feel you were treated with courtesy?

| Never | Some of the time | Most of the time | Always | No answer |
|--------|------------------|------------------|--------------|-----------|
| 0 (0%) | 2 (0.1%) | 44 (3.1%) | 1306 (93.4%) | 46 (3.3%) |

Q16 Did you feel your privacy was respected e.g. when being examined or during discussions with staff?

| Never | Some of the time | Most of the time | Always | No answer |
|----------|------------------|------------------|--------------|-----------|
| 5 (0.4%) | 10 (0.7%) | 74 (5.3%) | 1256 (89.8%) | 53 (3.8%) |

Q17 Were you aware of what to do if you wanted to make a complaint?

| Yes | No | No answer |
|-----------|-----------|-----------|
| 979 (70%) | 321 (23%) | 98 (7%) |

Q18 Please rate the following by circling your response:

| | 1 =Poor → 5 =Excellent | | | | | No answer |
|---|---|--------------|---------------|----------------|-----------------|--------------|
| | 1 | 2 | 3 | 4 | 5 | |
| The cleanliness of the premises | 16 (1.1%) | 2 (0.1%) | 5 (0.4%) | 104 (7.4%) | 1226 (87.7%) | 45 (3.2%) |
| The quality of the catering | 22 (1.6%) | 6 (0.4%) | 64 (4.6%) | 190 (13.6%) | 1050 (75.1%) | 66 (4.7%) |
| The activities available for you to participate in: | 27 (1.9%) | 27 (1.9%) | 105 (7.5%) | 306 (21.9%) | 859 (61.4%) | 74 (5.3%) |
| The general environment/surroundings: | 16 (1.1%) | 3 (0.2%) | 21 (1.5%) | 114 (8.2%) | 1196 (85.6%) | 48 (3.4%) |

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 |
|----------|------------------|------------------|--------------|-----------|
| 3 (0.2%) | 13 (0.9%) | 238 (17%) | 1098 (78.5%) | 46 (3.3%) |

4.4 Day-care Textual Comments (50 Hospices)

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

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 were about the service generally (519 comments made), followed by relieving anxiety, hospice transport, care staff, premises/ catering/ activities (all received over 300 comments). Many patients also made comments about the questionnaire (236 commented). In total 2288 comments were made by day-care patients.

While the responses were expected to identify areas where improvements might be made to the patient's experience, an over-whelming proportion of what patients wrote was positive and complimentary, showing how appreciative they were about many aspects of the care received. Only a fifth (21%) 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 (Q2)

A few comments were made about being unable to read the leaflet due to sight problems or feeling too stressed, and one suggested it should be displayed in a prominent place. Most comments were about the information included in leaflets.

Patients wanted to know more about what to expect when they entered the hospice. For example, the activities and other patients they would encounter, that they might feel anxious and tired at first, how they would be helped by others to settle in, or be given psychological and spiritual support. There were a few practical comments like ensuring a leaflet went to their carer, combining the six leaflets into one, using larger print, having the correct phone number, providing links to cancer user groups. One person said one-to-one complimentary therapy was actually not available, and another commented on the lack of visiting vicars.

Relieving anxiety (Q5)

The great majority of comments were complimentary, and a common theme was about their initial anxiety being dissipated:

'everyone was so exceptionally nice and caring within a few hours I felt so comfortable and relaxed'

'I had just been diagnosed and was very despondent but I was persuaded to come the following week and now wouldn't miss my Tuesday visit for anyone'

Some said they wanted to be greeted ('someone at the door to welcome you') and introduced better on arrival ('I feel they could have introduced people a bit more, I felt lost'). They also wanted more explanations both on arrival and in advance about the hospice and its routine, for example a video or a prior visit. A number wanted the opportunity to talk to somebody, one wanted a welcome drink, one felt a prayer would have been appropriate, and one likened the chairs in a room to an old people's home. On occasion there was too little to do, or too many helpers at one time. Others commented on the stigma attached to the word 'hospice', and problems with transport.

Transport (Q7)

Again most of the comments were complimentary, such as, *'all faultless'*, *'organisation is first-class. Volunteer drivers cannot be praised highly enough'*.

The problems patients had with transport included late-running and lack of comfort in some types of vehicle, with some vehicles described as dilapidated. There were specific comments about non-existent or withdrawn services and occasional problems with drivers. In particular patients liked continuity in the person driving, as they knew who to expect and the way they drove.

Care staff (Q9)

The question about confidence in the staff got the highest proportion of complimentary remarks, including:

'Beyond praise and always thoughtful'

'Difficult to imagine how it might be improved'

'They are wonderful'

A few critical comments were about volunteers not realising what was wanted. One person commented that staff should be more aware of patients' changing condition and needs for privacy, especially when *'some people are afraid to ask for help'*. There were also specific comments on feeling confused, lack of equipment and continuity of staff.

Care planning (Q10)

Patients had various suggestions on how they could be more involved in planning their care. For example by regular treatment planning or review meetings, seeing the hospice doctors regularly, having a more thorough discussion, staff talking more to patients rather than about them, getting more explanation about the treatment. Some commented that they were or had become less able to be involved due to their health or communication difficulties.

Explanations about care (Q11)

Regarding explanations about care, quite a few patients commented on how clear explanations were or how well they understood them. Suggestions included repeating information or reminding patients. Patients felt more time would help, especially one-to-one explanations. It was particularly important at the outset and if several agencies were involved that explanations were clear.

Cleanliness of premises, catering, activities, general environment/surroundings (Q18)

These questions elicited many comments, most of which were complimentary indicating how much patients looked forward to their visit. One person wrote:

'too much praise cannot be expressed by me – the words do not exist to give the ultimate praise so richly deserved'

There was quite a mix of comments about hospices in this section. They included the following:

Activities – would like more activities generally and on the day they visit. Suggestions included hairdresser, manicurist, complementary therapies, creative activities more suited to men/single people, more stimulating talks to keep brain active, inviting suggestions for activities, more trips out, more

volunteers to give help. Some had difficulty in participating, due to hearing problems or being heard, cannot get to hospice.

Premises – can be too hot/cold, needs re-decoration, don't like new premises, too small, more showers/baths, better privacy for bath/toilet, more space for wheelchairs/ walking aids. Parking problems and transport continued to be mentioned. Some were concerned that at times there were insufficient staff.

Catering – some had problems with eating or eating some foods. There were a few comments on wanting better quality food, a bigger meal, food served hot, and more sociability at meal-times.

Overall comments (Q20)

Again many comments were written, most of which were very positive about the care received. Some commented that they would like to attend Day-care more than once a week.

There was little new as patients continued to make remarks about activities and transport/parking. Specific suggestions however were made about access and space, adding a grab rail, having a box for donations and for their hospice to suggest ways of fundraising. One person wrote:

'offer me more opportunities to raise funds for the hospice and feel useful'

The Questionnaire (Q21)

236 comments were made about the questionnaire and three-quarters of these were positive, such as *'a very simple form to complete'*, *'seems to cover it all'*, *'very well put together'*. This is an unusually positive response from people who have been asked to complete questionnaires.

A small number (6) thought the questionnaire was too long, repetitive or difficult for them to complete, and a few (7) found parts of it unclear. Similarly small numbers commented on the formatting and layout. 8 people felt that questionnaires were not an appropriate way to get sensitive information, were unnecessary, a waste of time or failed to capture the *'well above excellent'* care received. Some just thought it was *'fair'*.

There was also quite a range of specific points made by one or two people, such as filling in the questionnaire took their mind off their illness, and one disliked receiving anything with the hospice postmark. Several people wanted to be asked about more topics (diet, menu, medical care, physio) or to be given more space for them or their carer to comment and give more details about themselves.

Overall the comments made about the questionnaire were positive, with some suggestions that can be used in future years.

5.Results: In-patient

The responses to the in-patient survey are given in sections as follows:

- 5.1 Individual hospice in-patient results
- 5.2 Benchmark in-patient results (5 hospices)
- 5.3 Average in-patient results overall (46 hospices)
- 5.4 In-patient textual comments (46 hospices)

The in-patient questionnaire is in Appendix B

5.1 Individual Hospice In-patient Results

(Individual hospice results were included in the reports given to each participating hospice)

5.2 Benchmark In-patient Results (5 hospices)

5 hospices reached the benchmark of 40 returned in-patient questionnaires and are included in the benchmark results. This section of the report gives an overview of the average results of these five hospices by presenting the results in tables, charts and a written commentary of the findings for each area covered by the survey: provision of information about services, staff communication and care, user involvement and understanding, the views of users on the support and courtesy of staff, views on the facilities and services and users experience when calling for assistance. The results, in table form, report the average of individuals from all five hospices aggregated together. The range of aggregated results for all five 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 answer to each question. The average results displayed in these tables are then reported visually in a bar-chart for each question. It is important to note when interpreting these results that answers for questions 8-14 were not available for 16 of the respondents for one of the benchmark hospices, these responses have therefore been recorded as 'no answer' and thus accounts for the higher level of no-answer given for these questions.

Provision of Information About In-patient Services

In-patients were asked whether they had looked at the information leaflet on the services that their hospice provides. Some hospices describe these as pamphlets or booklets. 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.

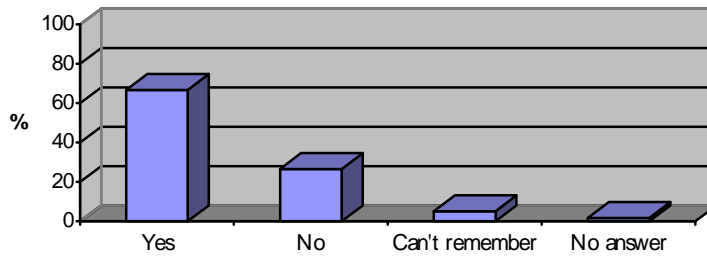
A third (66.7%) of in-patients who responded had looked at the information leaflet. The majority of in-patients in each benchmark hospice had seen the leaflet, although the proportion varies quite considerably (range: 52.5% - 80%). It appears that some in-patients are not seeing or reading the information leaflets provided.

Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on in-patient services, with the vast majority of patients who had looked at the leaflet reporting that it was easy to understand (96.9%), no-one felt that it wasn't easy to understand. They also felt that the leaflet included information that was helpful to them (90.1%). All of the patients who had looked at the leaflet described it as being easy to understand and all but one found it useful. Only 1.2%, equating to two patients, said that they found something to be incorrect in the leaflet and only 8% of patients who had looked at the leaflet had made a suggestion for including further or different information (for comments on incorrect leaflets and suggestions of more information see the 5.4 textual comments section of this report.

Q1 Before or during your time on the ward did you look at the information leaflet?

| | N | Average (%) | Range (%) |
|----------------|-----|-------------|-------------|
| Yes | 158 | 66.7 | 52.5 - 80 |
| No | 63 | 26.6 | 12.2 – 40.7 |
| Can't remember | 12 | 5.1 | 2 – 14.6 |
| No answer | 4 | 1.7 | 0 – 2.5 |
| Total | 237 | 100 | |

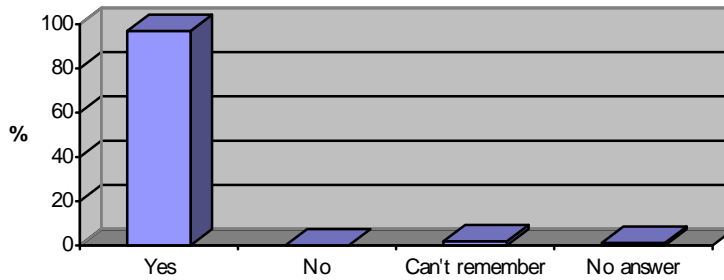
Q1 Before or during your time on the ward did you look at the information leaflet?



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

| | N | Average (%) | Range (%) |
|--------------------|-----|-------------|------------|
| Yes | 157 | 96.9 | 93.8 - 100 |
| No | 0 | 0 | 0 - 0 |
| Can't remember | 3 | 1.9 | 0 - 6.3 |
| No answer | 2 | 1.2 | 0 - 6.1 |
| Total | 162 | 100 | |
| Not applicable: 75 | | | |

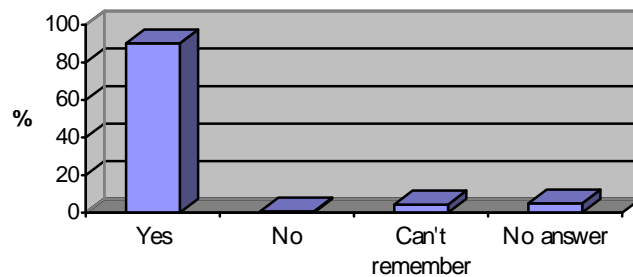
Q2a If you looked at the leaflet, was it easy to understand?



Q2b If you looked at the leaflet was it helpful?

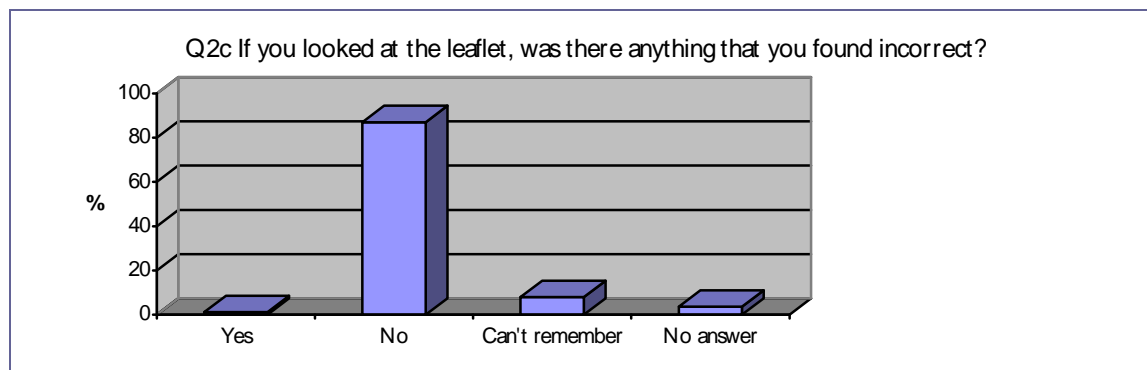
| | N | Average (%) | Range (%) |
|--------------------|-----|-------------|------------|
| Yes | 146 | 90.1 | 78.1 - 100 |
| No | 1 | 0.6 | 0 - 3.1 |
| Can't remember | 7 | 4.3 | 0 - 15.6 |
| No answer | 8 | 4.9 | 0 - 9.1 |
| Total | 162 | 100 | |
| Not applicable: 75 | | | |

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



Q2c If you looked at the leaflet was there anything that you found incorrect?

| | N | Average (%) | Range (%) |
|--------------------|-----|-------------|-----------|
| Yes | 2 | 1.2 | 0 – 3.3 |
| No | 141 | 87 | 77.8 – 95 |
| Can't remember | 13 | 8 | 0 – 15.6 |
| No answer | 6 | 3.7 | 0 – 11.1 |
| Total | 162 | 100 | |
| Not applicable: 75 | | | |



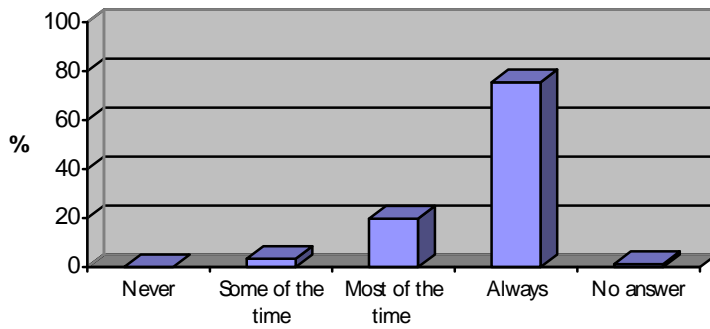
In-patient Staff Communication and Care

The survey asked in-patients about the communication and care they had received from staff on the ward. The majority (75.5%) of respondents reported that staff involved in their care always introduced themselves. A further 19.8% said they introduced themselves most of the time and no one reported that staff had never introduced themselves. As well as an introduction staff were also frequently explaining to the patient what they were doing when caring for them. 74.7% reported that staff always explained what they were doing, 20.3% reported most of the time, and no one reported that staff had never explained what they were doing. In-patients were also asked whether they had confidence in the staff who were caring for them overall. Again the response was very positive with 84.8% reporting this always to be the case, and 13.1% most of the time. Respondents were invited to make further comments on their confidence in staff, which can be found in the 5.4 textual comments section of this report.

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

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 8 | 3.4 | 0 – 7.5 |
| Most of the time | 47 | 19.8 | 15.2 – 23.7 |
| Always | 179 | 75.5 | 71.2 - 80.4 |
| No answer | 3 | 1.3 | 0 – 2.5 |
| Total | 237 | 100 | |

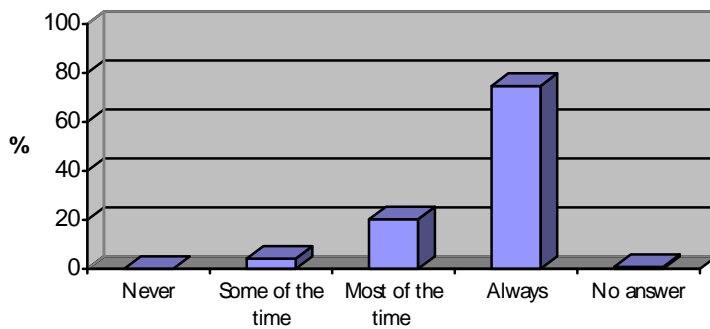
Q3a While you were an in-patient, did staff involved in your care introduce themselves?



Q3b. While you were an in-patient, did staff explain what they were doing?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 10 | 4.2 | 0 – 8.5 |
| Most of the time | 48 | 20.3 | 17.6 – 25 |
| Always | 177 | 74.7 | 67.5 – 78.4 |
| No answer | 2 | 0.8 | 0 – 2.5 |
| Total | 237 | 100 | |

Q3b While you were an in-patient, did staff explain what they were doing?



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

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 3 | 1.3 | 0 – 2.5 |
| Most of the time | 31 | 13.1 | 8.7 – 15.7 |
| Always | 201 | 84.8 | 82.4 – 91.3 |
| No answer | 2 | 0.8 | 0 – 2.5 |
| Total | 237 | 100 | |



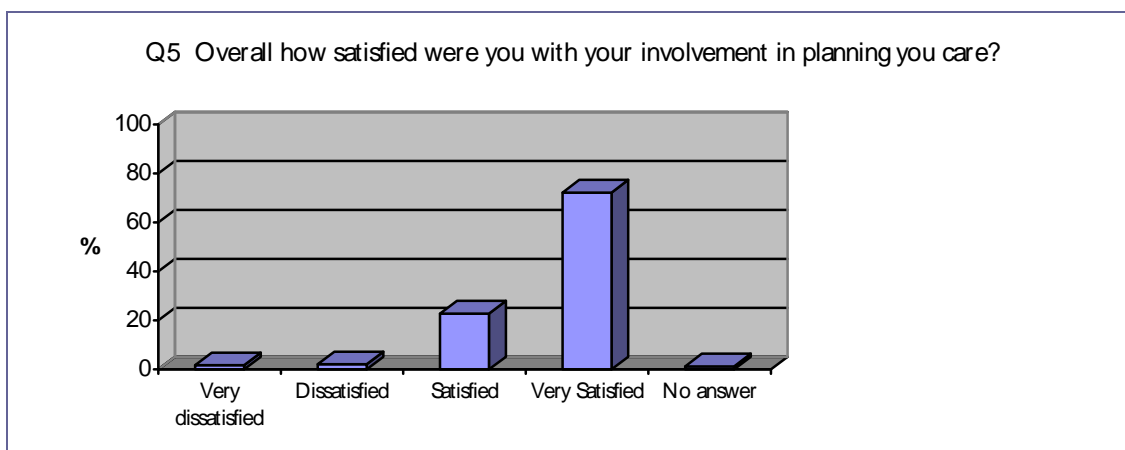
In-patient Involvement and Understanding

Respondents were asked about their overall satisfaction with their involvement in the planning of their care while on the ward as an in-patient. 72.2% of respondents were very satisfied, and 22.8% were satisfied with the level of involvement in their care. Of the small proportion who were either dissatisfied or very dissatisfied only four respondents made suggestions as to how their hospice could involve them more (for these suggestions of more information see the 5.4 textual comments section of this report).

The survey also asked about users understanding of the explanations given to them about their care whilst in day-care. 62.4% of respondents felt that they always understood the explanations given to them, and 30.8 said they understood most of the time. Only 8.4% of respondents suggested ways of making their hospice's explanations clearer. (for suggestions see the 5.4 textual comments sections in this report). 81% of respondent's felt that they were always given the opportunity to ask questions when they want to, and the opportunity was given most of the time to 11.8%, which is useful if an explanation isn't understood. In terms, of the time allowed for patients to make decisions regarding their care, 62.9% felt that they were always given enough time to make a decision, and 17.7% felt they had enough time most of the time. The patient's experience of always having enough time for decision making was varied among the individual benchmark hospices (range: 48.8-72.5).

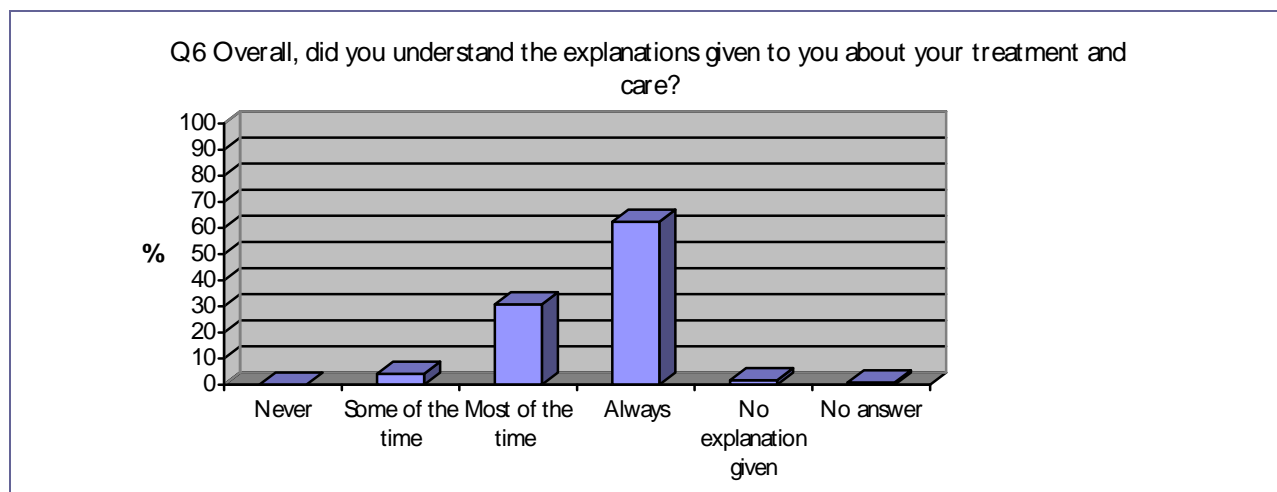
Q5 Overall how satisfied were you with your involvement in planning your care?

| | N | Average (%) | Range (%) |
|-------------------|-----|-------------|-------------|
| Very dissatisfied | 4 | 1.7 | 0 – 2.5 |
| Dissatisfied | 5 | 2.1 | 0 – 5.1 |
| Satisfied | 54 | 22.8 | 13.7 – 27.1 |
| Very Satisfied | 171 | 72.2 | 66.1 – 82.4 |
| No answer | 3 | 1.3 | 0 – 2.5 |
| Total | 237 | 100 | |



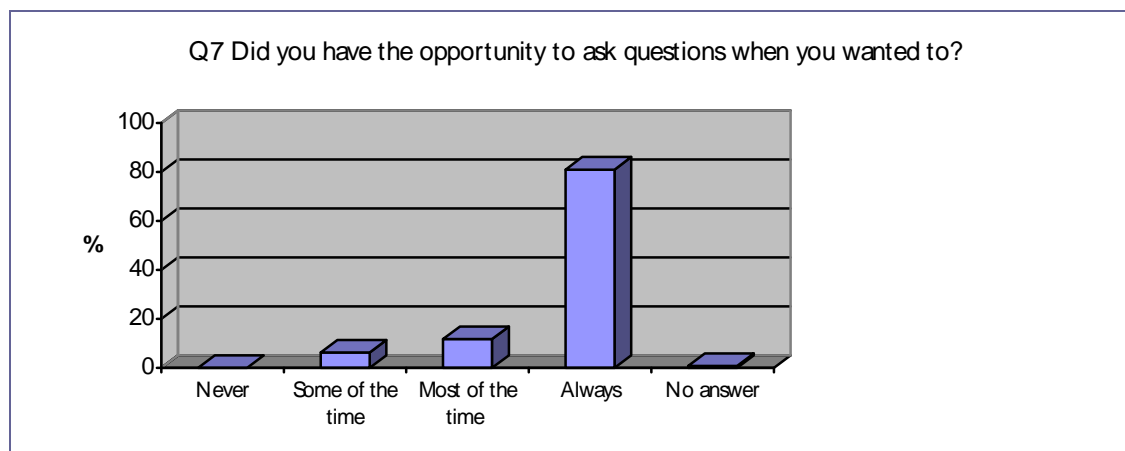
Q6 Overall, did you understand the explanations given to you about your treatment and care?

| | N | Average (%) | Range (%) |
|----------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 - 0 |
| Some of the time | 10 | 4.2 | 0 - 7.5 |
| Most of the time | 73 | 30.8 | 22 - 39.1 |
| Always | 148 | 62.4 | 52.5 - 70.7 |
| No explanation given | 4 | 1.7 | 0 - 3.4 |
| No answer | 2 | 0.8 | 0 - 2.5 |
| Total | 237 | | |



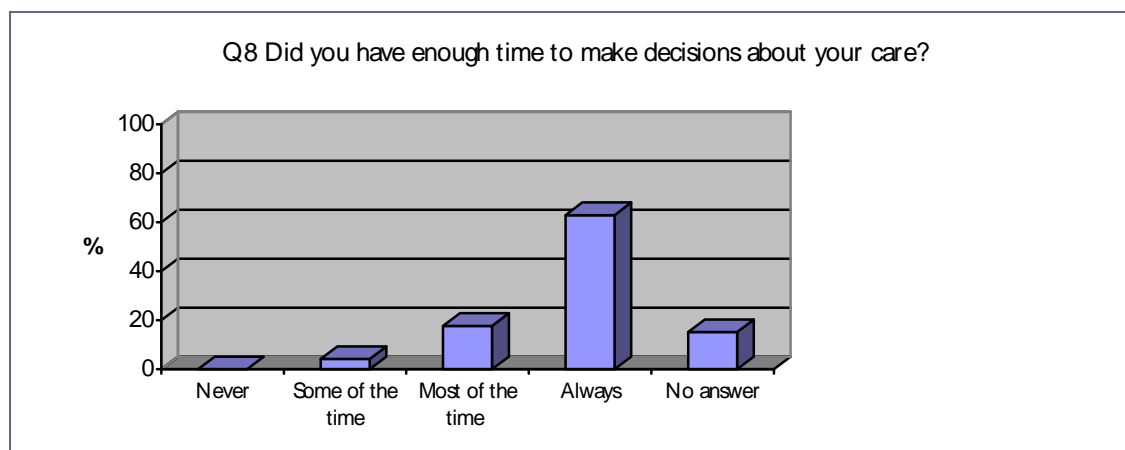
Q7 Did you have the opportunity to ask questions when you wanted to?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 - 0 |
| Some of the time | 15 | 6.3 | 2.4 - 12.5 |
| Most of the time | 28 | 11.8 | 4.9 - 18.6 |
| Always | 192 | 81 | 72.9 - 90.2 |
| No answer | 2 | 0.8 | 0 - 2.5 |
| Total | 237 | 100 | |



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

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 10 | 4.2 | 2.2 – 5.9 |
| Most of the time | 42 | 17.7 | 9.8 – 26.1 |
| Always | 149 | 62.9 | 48.8 – 72.5 |
| No answer | 36 | 15.2 | 8.5 - 39 |
| Total | 237 | 100 | |

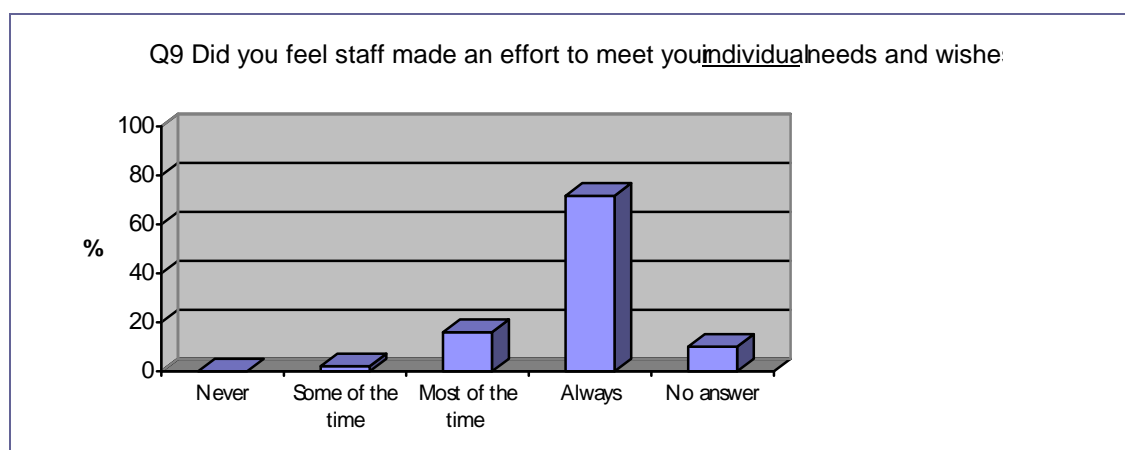


Views of In-patients on the Support and Courtesy of Staff

A number of questions were asked in the survey about in-patient views on the support and courtesy of the staff looking after them on the ward. Generally respondents were very positive in the support they received from staff. 71.7% felt that staff always made an effort to meet their individual needs and wishes, and 16% felt they did most of the time. No one felt that staff never made an effort. In-patients generally felt that staff were always courteous and respected their privacy: 85.2% felt they were always treated with courtesy and 81% felt that their privacy was always respected, for example when being examined or during discussions with staff. Only two respondents felt that their privacy was never respected.

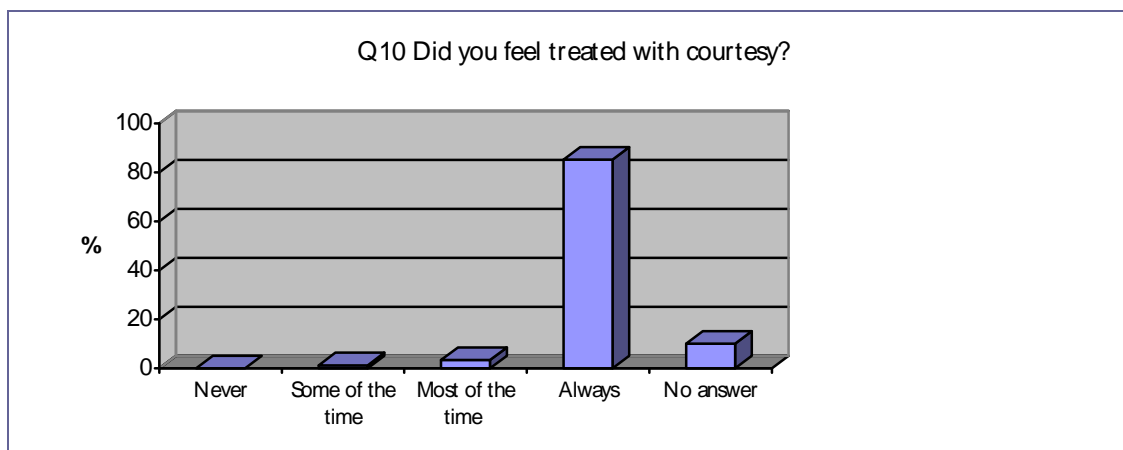
Q9 Did you feel staff made an effort to meet your individual needs and wishes?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 5 | 2.1 | 0 – 5 |
| Most of the time | 38 | 16 | 7.3 – 19.6 |
| Always | 170 | 71.7 | 53.7 – 78.3 |
| No answer | 24 | 10.1 | 1.7 - 39 |
| Total | 237 | 100 | |



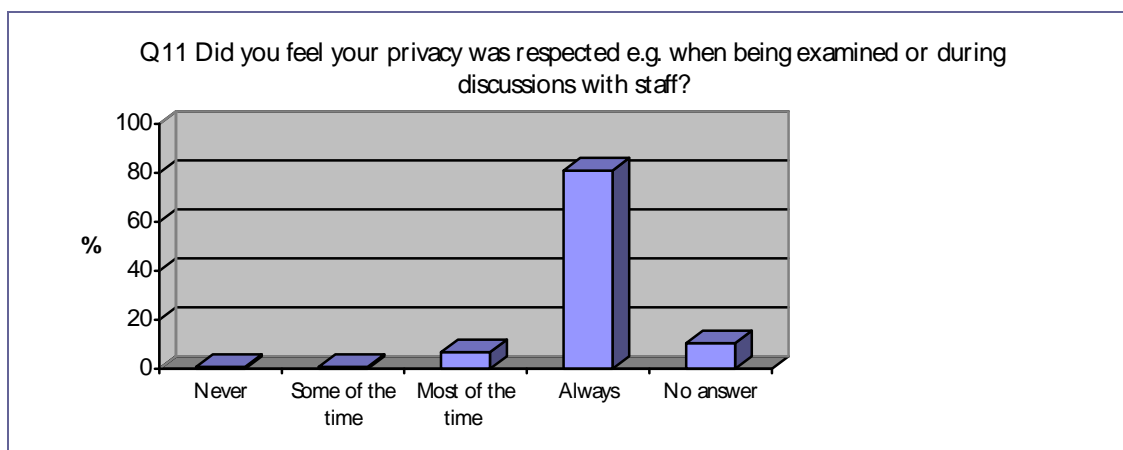
Q10 Did you feel you were treated with courtesy?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-----------|
| Never | 0 | 0 | 0 – 0 |
| Some of the time | 3 | 1.3 | 0 – 2.2 |
| Most of the time | 8 | 3.4 | 0 – 10 |
| Always | 202 | 85.2 | 61 – 91.5 |
| No answer | 24 | 10.1 | 1.7 - 39 |
| Total | 237 | 100 | |



Q11 Did you feel your privacy was respected e.g. when being examined or during discussions with staff?

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 2 | 0.8 | 0 – 2.2 |
| Some of the time | 2 | 0.8 | 0 – 2.2 |
| Most of the time | 16 | 6.8 | 2 – 12.5 |
| Always | 192 | 81 | 56.1 - 89.8 |
| No answer | 25 | 10.5 | 1.7 - 39 |
| Total | 237 | 100 | |



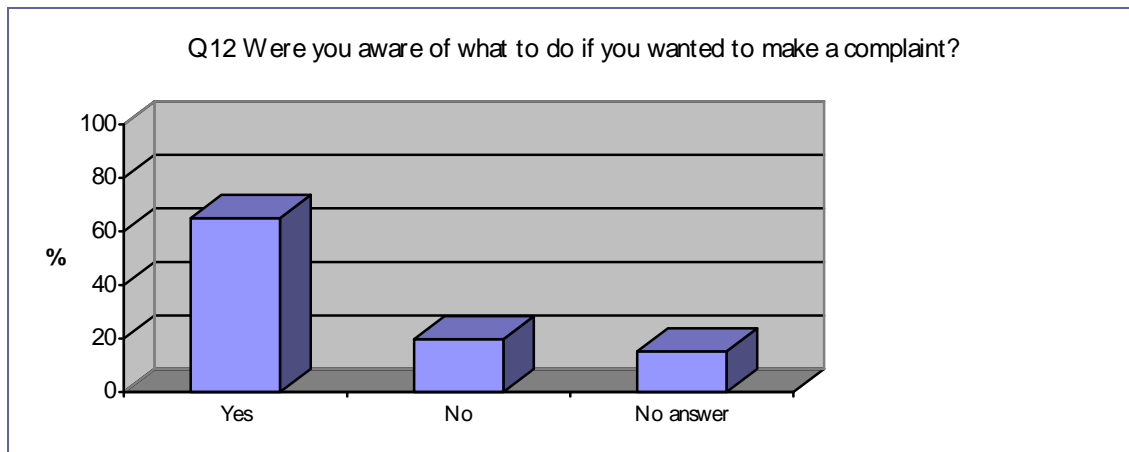
In-patient Facilities and Services

The survey concentrated on general questions about facilities and services available to in-patients, which would be applicable to all hospices. It asked about awareness of facilities available to make a complaint, what they thought about the quality of the catering, access to food other than at set meal times, and also views on the hospice/ward building itself by asking questions about the general environment/surroundings and the cleanliness of the premises.

Two thirds of respondents (65%) were aware of how to make a complaint compared to 19.8% who were not. When asked to rate the following facilities and services they were viewed by the majority to be of a high standard and rated as excellent: the cleanliness of the premises (78.5%), the quality of the catering (65.4%), the access to food other than at set meal times (54%) and the general environment and surroundings (78.9%). Only access to food other than at meal times was rated as poor, and then only by one respondent. However it appears there is room for improvement as only just over half the respondents rated this service as excellent, which is a much lower rating compared to that of other services and facilities. On the other hand ratings of excellent were also quite variable among the benchmark hospices individually for the other facilities and services so there is also room for improvement for some hospices in these areas also. 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.

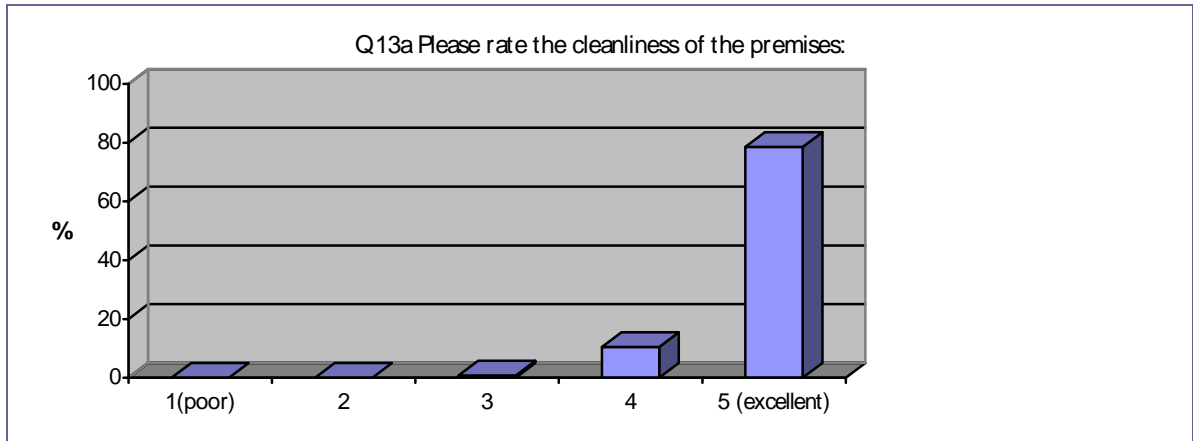
Q12 Were you aware of what to do if you wanted to make a complaint?

| | N | Average (%) | Range (%) |
|-----------|-----|-------------|------------|
| Yes | 154 | 65 | 53.7-77.5 |
| No | 47 | 19.8 | 0 – 28.8 |
| No answer | 36 | 15.2 | 4.3 – 46.3 |
| Total | 237 | 100 | |



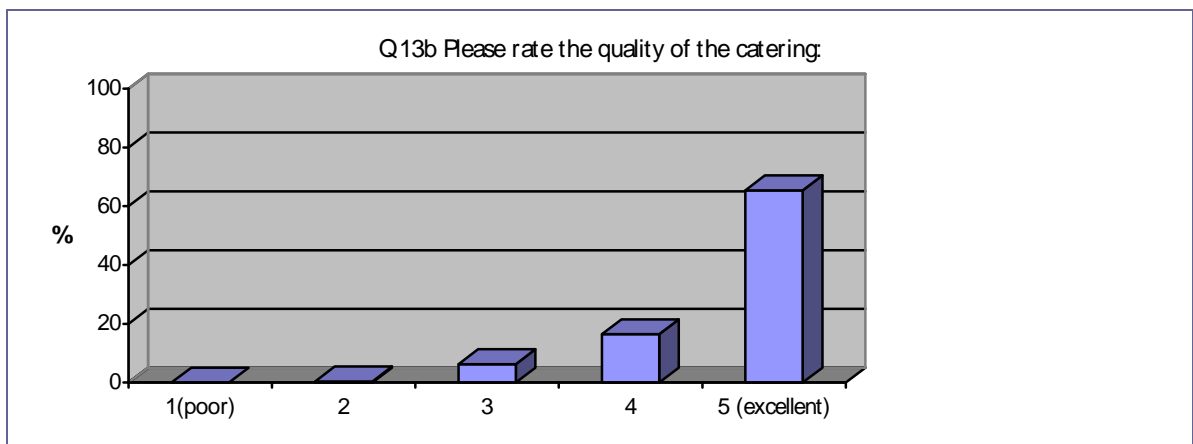
Q13a Please rate the cleanliness of the premises:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|-------------|
| 1. Poor | 0 | 0 | 0 – 0 |
| 2. | 0 | 0 | 0 – 0 |
| 3. | 2 | 0.8 | 0 – 3.4 |
| 4. | 25 | 10.5 | 2 – 19.5 |
| 5. Excellent | 186 | 78.5 | 41.5 – 90.2 |
| No answer | 24 | 10.1 | 1.7 - 39 |
| Total | 237 | 100 | |



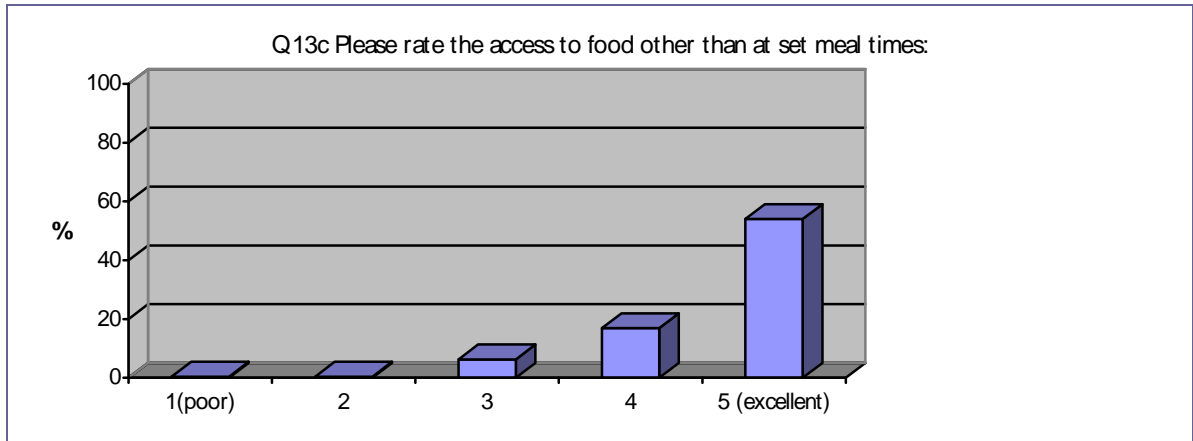
Q13b Please rate the quality of the catering:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|-------------|
| 1. Poor | 0 | 0 | 0 – 0 |
| 2. | 1 | 0.4 | 0 – 2.2 |
| 3. | 15 | 6.3 | 0 – 11.9 |
| 4. | 39 | 16.5 | 10.9 – 21.6 |
| 5. Excellent | 155 | 65.4 | 39 – 77.5 |
| No answer | 27 | 11.4 | 1.7 – 41.5 |
| Total | 237 | 100 | |



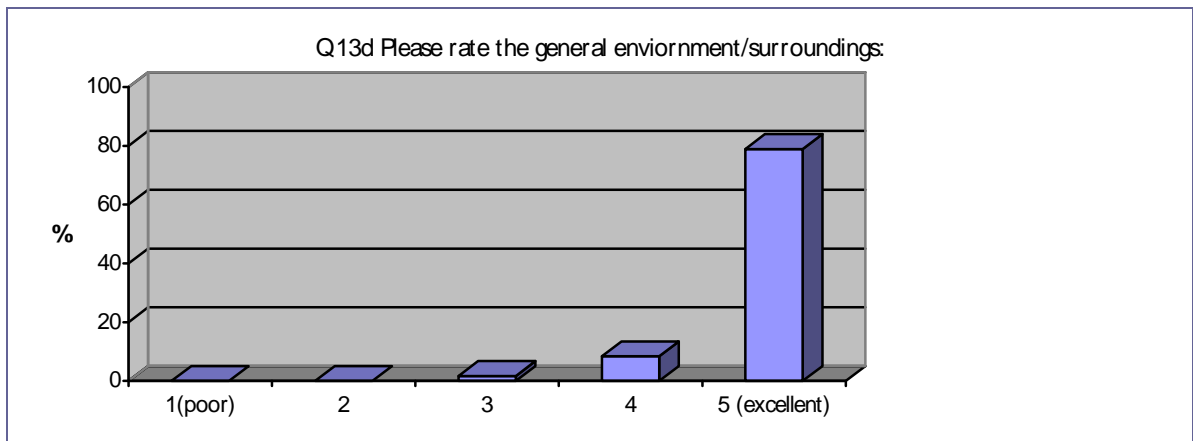
Q13c Please rate the access to food other than at set meal times:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|-------------|
| 1. Poor | 1 | 0.4 | 0 – 1.7 |
| 2. | 1 | 0.4 | 0 – 2 |
| 3. | 15 | 6.3 | 2.4 – 11.9 |
| 4. | 40 | 16.9 | 9.8 – 22.5 |
| 5. Excellent | 128 | 54 | 41.5 – 60.9 |
| No answer | 52 | 21.9 | 11.8 – 46.3 |
| Total | 237 | 100 | |



Q13d Please rate the general environment/surroundings:

| | N | Average (%) | Range (%) |
|--------------|-----|-------------|------------|
| 1. Poor | 0 | 0 | 0 – 0 |
| 2. | 0 | 0 | 0 – 0 |
| 3. | 4 | 1.7 | 0 – 3.9 |
| 4. | 20 | 8.4 | 0 – 17.1 |
| 5. Excellent | 187 | 78.9 | 39 – 89.8 |
| No answer | 26 | 11 | 1.7 – 41.5 |
| Total | 237 | 100 | |

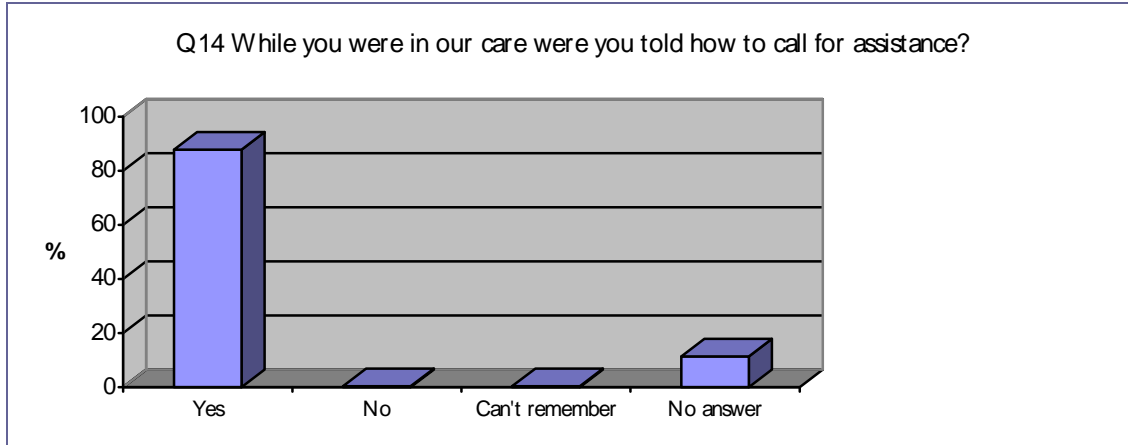


In-patients Calling for Assistance

The majority of in-patients (87.8%) were told how to call for assistance while they were in hospice care. Only one respondent reported that they were not told. 22 respondents (9.3%) did not need to call for assistance, when they were an in-patient. Of those who did need to call for assistance the majority (75.8%) were always satisfied with the response they got, and 17.7% were satisfied most of the time.

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

| | N | Average (%) | Range (%) |
|----------------|-----|-------------|-------------|
| Yes | 208 | 87.8 | 58.5 – 96.6 |
| No | 1 | 0.4 | 0 – 2.5 |
| Can't remember | 1 | 0.4 | 0 – 2 |
| No answer | 27 | 11.4 | 2.5 – 41.5 |
| Total | 237 | 100 | |



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

| | N | Average (%) | Range (%) |
|------------------|-----|-------------|-------------|
| Never | 0 | 0 | 0 - 0 |
| Some of the time | 4 | 1.9 | 0 – 3.8 |
| Most of the time | 38 | 17.7 | 10.3 – 22.2 |
| Always | 163 | 75.8 | 71.7 – 84.6 |
| No answer | 10 | 4.7 | 2.2 – 8.1 |
| Total | 215 | 100 | |

Not applicable as did not need to call for assistance: 22



5.3 Average In-patient Results Overall (46 Hospices)

The following results report the average of individuals aggregated together from all 46 hospices who took part in the in-patient questionnaire at discharge. The total number of returned questionnaires received from in-patients was 926.

| |
|-------------------------------|
| Service: In-patient N: 926 |
|-------------------------------|

Q1 During your time on the ward did you look at the information leaflet?

| Yes: | No | Can't remember | No answer |
|-------------|-------------|----------------|-----------|
| 576 (62.2%) | 254 (27.4%) | 74 (8%) | 22 (2.4%) |

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

| Yes | No | Can't remember | No answer |
|---------------------|----------|----------------|-----------|
| 570(95.3%) | 2 (0.3%) | 10 (1.7%) | 16 (2.7%) |
| Not applicable: 328 | | | |

Q2b If you looked at the leaflet was it helpful?

| Yes | No | Can't remember | No answer |
|---------------------|----------|----------------|-----------|
| 552 (92.3%) | 2 (0.3%) | 16 (2.7%) | 28 (4.7%) |
| Not applicable: 328 | | | |

Q2c If you looked at the leaflet was there anything that you found incorrect?

| Yes | No | Can't remember | No answer |
|---------------------|-------------|----------------|-----------|
| 12 (2%) | 517 (86.5%) | 39 (6.5%) | 30 (5%) |
| Not applicable: 328 | | | |

Q3a While you were an in-patient did staff involved in your care introduce themselves?

| Never | Some of the time | Most of the time | Always | No answer |
|--------|------------------|------------------|-----------|-----------|
| 0 (0%) | 31 (3.3%) | 164 (17.7%) | 713 (77%) | 18 (1.9%) |

Q3b While you were an in-patient did staff explain what they were doing?

| Never | Some of the time | Most of the time | Always | No answer |
|----------|------------------|------------------|-------------|-----------|
| 4 (0.4%) | 27 (2.9%) | 182 (19.7) | 697 (75.3%) | 16 (1.7%) |

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

| Never | Some of the time | Most of the time | Always | No answer |
|--------|------------------|------------------|-------------|-----------|
| 0 (0%) | 12 (1.3%) | 96 (10.4%) | 808 (87.3%) | 10 (1.1%) |

Q5 Overall how satisfied were you with your involvement in planning your care?

| Very dissatisfied | Dissatisfied | Satisfied | Very satisfied | No answer |
|-------------------|--------------|-------------|----------------|-----------|
| 15 (1.6%) | 8 (0.9%) | 227 (24.5%) | 659 (71.2%) | 17 (1.8%) |

Q6 Overall, 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 |
|----------|------------------|------------------|-----------|----------------------|-----------|
| 2 (0.2%) | 26 (2.8%) | 244 (26.3%) | 630 (68%) | 8 (0.9%) | 16 (1.7%) |

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 |
|----------|------------------|------------------|-------------|-----------|
| 4 (0.4%) | 26 (2.8%) | 151 (16.3%) | 725 (78.3%) | 20 (2.2%) |

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

| Never | Some of the time | Most of the time | Always | No answer |
|----------|------------------|------------------|-------------|-----------|
| 5 (0.5%) | 34 (3.7%) | 178 (19.2%) | 625 (67.5%) | 84 (9.1%) |

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 |
|----------|------------------|------------------|-------------|-----------|
| 1 (0.1%) | 14 (1.5%) | 126 (13.6%) | 729 (78.7%) | 56 (6%) |

Q10 Did you feel you were treated with courtesy?

| Never | Some of the time | Most of the time | Always | No answer |
|--------|------------------|------------------|-------------|-----------|
| 0 (0%) | 7 (0.8%) | 45 (4.9%) | 831 (89.7%) | 43 (4.6%) |

Q11 Did you feel your privacy was respected 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%) | 6 (0.6%) | 55 (5.9%) | 816 (88.1%) | 47 (5.1%) |

Q12 Were you aware of what to do if you wanted to make a complaint?

| Yes | No | No answer |
|-------------|-------------|------------|
| 655 (70.7%) | 175 (18.9%) | 96 (10.4%) |

Q13 Please rate the following by circling your response:

| | 1 =Poor → 5 =Excellent | | | | | No answer |
|--|---|-----------|-----------|-------------|-------------|-----------|
| | 1 | 2 | 3 | 4 | 5 | |
| The cleanliness of the premises | 4 (0.4%) | 0 (0%) | 7 (0.8%) | 105 (11.3%) | 768 (82.9%) | 42 (4.5%) |
| The quality of the catering | 3 (0.3%) | 8 (0.9%) | 45 (4.9%) | 164 (17.7%) | 649 (70.1%) | 57 (6.2%) |
| Access to food other than at set meal times: | 9 (1%) | 13 (1.4%) | 48 (5.2%) | 190 (20.5%) | 546 (59%) | 120 (13%) |
| The general environment/surroundings: | 3 (0.3%) | 3 (0.3%) | 12 (1.3%) | 84 (9.1%) | 777 (83.9%) | 47 (5.1%) |

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

| Yes | No | Can't remember | No answer |
|-------------|-----------|----------------|-----------|
| 850 (91.8%) | 13 (1.4%) | 8 (0.9%) | 55 (5.9%) |

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

| Never | Some of the time | Most of the time | Always | No answer |
|---|------------------|------------------|-------------|-----------|
| 1 (0.1%) | 12 (1.4%) | 120 (14%) | 684 (79.9%) | 39 (4.6%) |
| Did not need to call for assistance: 70 | | | | |

5.4. In-patient Textual Comments (46 Hospices)

Each participating hospice has been given in-patients' comments about their individual hospice. This section summarises in-patients' comments across all the hospices involved in the in-patient survey.

The questionnaire had space for patients to write in and elaborate their answers. For example, to say in what way patients found information leaflets difficult to understand or unhelpful, or to elaborate on their 'ticked box' answers. Numerous comments were received about information, care staff, explanations about care, catering and premises/ general environment/ surrounding.

Many comments were highly favourable, and overall there were only 271 (27%) out of a total of 1019 comments that identified issues for hospices to address. The summary of the comments that follows focuses on the latter, and it should be noted that many of these are made by one or two people only.

Information leaflets (Q2)

While comments were not very numerous in this section, a higher proportion of them might be of use to hospices. In-patients were more likely to have problems taking information in due to their health, being blind or having anxieties on arrival.

Some felt there was insufficient detail, or the leaflet mentioned things that were inaccurate (staff names, no chaplain, quiet day changed), or irrelevant (information about hospital and not the hospice).

Some suggestions were for a contents list, more information about public transport, about what they should take, amenities for visiting and visitors, for a floor plan, more activities at weekends, use of telephone. Other requests were for a brief verbal overview or other audio format. In-patients were also interested in background information about the hospice, how it was founded, financed and how much it costs to run. Some asked about procedures for complaints and demonstrations of security systems.

Care staff (Q4)

The comments about confidence in staff were overwhelmingly positive, such as:

'Boosted my confidence with attention to detail and amount of knowledge the staff has.'

'Exceptional care and understanding'

'I felt very safe and that all members of staff – medical, nursing and ancillary – were concerned for both physical and psychological health at all times.'

'cannot fault anything at all'

Compared to day-care patients there were more negative comments about staff, mainly centred around being too busy and short of time, which led to occasional brusqueness and lack of sympathy. Other comments were about not seeing name badges, there being no consultant, and quite a few observations about staff not having appropriate skills, e.g. patient allowed to fall, not noticing catheter was blocked, poorly trained in handling patient, not using equipment properly.

Care planning (Q5)

Although only a few comments were made, they did point to problems in communication. In-patients wanted to be listened to and have more direct communication with qualified staff. They wanted more time from nursing staff and better planning of what they needed in advance. Two comments were critical of specific staff members.

Explanations about care (Q6)

In-patients wanted more information in writing, especially at times when they are feeling confused and unable to retain information. Other suggestions included the use of simple language, for explanations to be repeated, explanations to be given to relatives or carers if find it difficult to retain, for staff to take more time to explain and take into account individual problems with hearing or memory.

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

This section of the questionnaire prompted many positive comments, including:

'The whole experience was totally different than I expected. Everything was excellent. Thank you. All staff including domestics were very cheerful and helpful.'

'care and kindness second to none'

'xxx hospice is the next step to heaven wonderful in every way'

'the hospice was beyond my wildest dreams, a true haven of peace and serenity, and staff on your journey with you. All from a special mould.'

A poor standard of cleanliness was remarked upon by one or two people.

Catering generated quite a number of complaints about specific foods or the way they were served and cooked, others wanted more vegetarian options, earlier mealtimes, etc. One suggested having a small snack bar including microwave facilities.

Other comments about facilities included the need for up-grading, more baths/showers, various problems with hot water, late-running bath-times, wanting a TV, no seating/coat-hooks for visitors, poor access for wheelchairs. Noise was quite an issue with noisy trolleys, TVs and extractor fans at night mentioned.

There was also a comment about a lack of staff and having no doctor on duty at a weekend and during the night, another respite patient felt the allocated ward was inappropriate.

A few comments were about wanting more activities, e.g. one person wanted arts and crafts, and another wanted activities to relieve boredom.

Overall comments (Q15)

At the end of the questionnaire many in-patients took the opportunity to make remarks about the hospice stay overall, and the majority of these were favourable:

'how does one improve on excellent?'

'An excellent service for patient and families alike'

'Is a smile a condition of employment?'

'I would always recommend the hospice to anyone. I was terrified but no more.'

Among the more critical comments, the same overall problems were raised that had appeared in earlier sections of the questionnaire, such as parking facilities, noise, food, bathing facilities, staff numbers and communication.

Some additional issues were raised about the hospice needing more money, facilities and publicity in addition to staff. There were comments about things being placed out of reach or being out of service, needing more space, about there being too few senior staff at night and lack of continuity of staff contributing to poor handover of information of patient needs. Some suggestions were made about having more facilities (hydro-electric pool, exercise opportunities, newspapers, internet access, Sky TV, etc) and generating more local awareness of the hospice. One person wrote:

'Please involve both the local and business communities by explaining what you do. Most people have that impression that once you go in you don't come out. I'm sure this would make fundraising easier to accomplish'.

It was also suggested that active people should be placed among people with similar capabilities, and that there was better planning of discharge with relatives or carers.

The views on volunteers was mixed – sometimes too many, or suggesting getting more in at weekends.

The Questionnaire (Q16)

103 comments were made about the questionnaire and all but 13 were complimentary. The small number of problems included needing assistance to complete it, or unsure how to complete it. The following were each said by one person: 'too repetitive', 'save paper – do double-sided', there was a missing question, and it did not touch on the ethos of palliative care that was the most important and distinctive thing that set the hospice apart.

6. Discussion

The reports given to each participating hospices enables them to look at their own individual hospice results and compare themselves against the benchmark hospice results. Individual hospices can then benefit from seeing how well they 'fit' with other hospices who received a high response from the survey.

Aggregated results for the benchmark hospices and all participating hospices overall were very positive whether in a day-care or in-patient ward setting and similar patterns emerged from both sets of results. Day-care and in-patient services were both considered excellent and of a high standard in a number of broad areas, including the information provided, the care provided by staff, patient involvement, and facilities available.

Praise for hospice staff was particularly high in relation to the courtesy and respect of staff towards patients, and the patients had confidence in the staff who were caring for them. Two thirds of respondents reported that staff always explained what they were doing, and to report that they were always given an opportunity to ask questions. This may be due to the nature of in-patient care and treatment being more complex and staying in the hospice for a longer period of time rather than the short visits provided by day-care services, thus in-patients may have more questions and worries that need to be answered.

There were some differences to note. More in-patients than day-care patients had looked at information leaflets but both figures were quite low. In-patients were less likely to report that they always understood the explanation given to them about their treatment and care, compared to day-care patients. This may be due to the different level of complexity of the treatment and care, However it is important to recognise that despite these differences the level of satisfaction with all of these areas was extremely high for both in-patient and day-care patients.

There were some weaker service areas in comparison to others, but these were still highly rated by the majority of patients overall. For example the level of satisfaction with patients involvement in their care may suggest, if appropriate, a need for increased patient participation, as well as increasing the time allowed to make decisions for in-patients. Further awareness of complaints procedures may also be necessary. It appears that for some patients there is room to improve the quality of the catering, particularly the access of food other than at set meal times for in-patients. For day-care patients specifically, the areas of service that were least satisfactory were the activities available to participate in and the amount of support provided if a group member was discharged or died. In-patients were not asked these particular questions.

Judging from the written comments a similar pattern emerges with hospice patients being extremely satisfied with their care and full of praise for the staff. Some of the comments raised issues that hospices may wish to address, for example comments and suggestions frequently covered practical problems, such as transport, food, activities and facilities, but they also included issues about staffing levels and performance. The proportion of negative comments on comparable issues were slightly greater for in-patients than for day-care patients, apart from comments on the questionnaire itself. In-patients were more concerned with the way staff communicated with them about their condition and care plans. Day-care patients were much more likely to comment on transport issues and the activities they would like available. They also mentioned in patient comments that their initial fears and anxieties of going to the hospice were soon dealt with.

7. Implications for Future Research

- That the survey should be repeated regularly to seek views of patients on the quality of the treatment and care provided as is required by the Healthcare commission. The Healthcare Commission requested that a patient survey is carried out annually, as a minimum, however experience from this survey suggests that it may be more realistic to consider conducting a survey on this scale less than annually to allow time to collect the required data, analyse and disseminate results.
- The survey should be repeated so that individual hospices participating in the survey can measure change in their quality of treatment and care over time.
- Qualitative research, such as patient focus groups, could be conducted by individual hospices to discuss key areas identified by the survey where improvement is needed. Key areas identified within some hospices were catering services, day-care transport services, activities, user involvement in care and treatment, information giving and understanding.

DAYCARE QUESTIONNAIRE

Hospice Code

Here at **(enter name of hospice here)** we are keen to ensure that the services we provide meet your needs. We would be very grateful if you could spare the time to complete this short anonymous questionnaire about your experience with us. Please be open with your responses, as it will give us vital 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)**, did you look at a leaflet called **(enter name of information here)**?

- No go to question 3
- Yes go to question 2
- Can't remember go to question 3

2. If you looked at the leaflet :

a) Was the leaflet easy to understand?

- No
- Yes
- Can't remember

If you ticked "No" please give further details

.....

b) Was the leaflet helpful?

- No
- Yes
- Can't remember

If you ticked "No" please give further details

.....

c) Was there anything in the leaflet that you found incorrect?

- No
- Yes
- Can't remember

If you ticked "Yes" please give further details

.....

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

DAYCARE QUESTIONNAIRE

Hospice Code

.....
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)

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

Poor —————> Excellent

| | | | | | |
|----------------------|---|---|---|---|---|
| Promptness of pickup | 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 further comments on the hospice transport?

.....

8a. While you were in Daycare at (enter name of hospice here), did 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 name of hospice here), did staff explain what they were doing?

- Never
- Some of the time
- Most of the time
- Always

DAYCARE QUESTIONNAIRE

Hospice Code

9. Overall 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 further comments regarding this?

.....

10. Overall how satisfied were you with your involvement in planning your care?

- Very dissatisfied
- Dissatisfied
- Satisfied
- Very Satisfied

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

.....


11. Overall, did you understand the explanations given to you about your care provided whilst at Day Care (this does not include the care provided by your GP or hospital)

- Never
- Some of the time
- Most of the time
- Always
- No explanations given

Is there any way of making our explanations clearer?

.....

12. How supported did you feel when a group member was discharged or died? (please tick the box closest to your view)

Totally  Extremely Supported

- 1 2 3 4 5

Not applicable to me as no one has died or been discharged while I have been attending Daycare

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

- Never
- Some of the time
- Most of the time
- Always

DAYCARE QUESTIONNAIRE

Hospice Code

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 courtesy?

- Never
- Some of the time
- Most of the time
- Always

16. Did you feel your privacy was respected e.g. when being examined or during discussions with staff ?

- Never
- Some of the time
- Most of the time
- Always

17. Were you aware of what to do if you wanted to make a complaint?

- No
- Yes

18. Please rate the following by circling your response:(1 = poor 5 = excellent)

Poor \longrightarrow Excellent

| | | | | | |
|--|---|---|---|---|---|
| The cleanliness of the premises | 1 | 2 | 3 | 4 | 5 |
| The quality of the catering | 1 | 2 | 3 | 4 | 5 |
| The activities available for you to participate in | 1 | 2 | 3 | 4 | 5 |
| The general environment/surroundings | 1 | 2 | 3 | 4 | 5 |

Do you have any further comments?

.....
.....

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

DAYCARE QUESTIONNAIRE

Hospice Code

20. Do you have any further comments or suggestions to help us to improve our Daycare service? (please write below)

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

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

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

Please return the completed questionnaire in the pre paid envelope provided or directly to :

Charlotte Hastie, Centre for Health Services, George Allen Wing, University of Kent ,
Kent, CT2 7NF

Anonymous results of this questionnaire and any actions it has prompted will be available (enter details as appropriate for your hospice)

Thank you again for your help.

Please call (enter details of Daycare clinical manager here) if you wish to contact (enter name of hospice here) with any concerns regarding your care.

INPATIENT QUESTIONNAIRE

Hospice Code

Here at **(enter name of hospice here)** we are keen to ensure that the services we provide meet your needs. We would be very grateful if you could spare the time to complete this short anonymous questionnaire about your experience with us. Please be open with your responses, as it will give us vital information to help us plan for the future.

Many thanks for your time.

1. During your time on the ward at **(enter name of hospice here)** did you look at a leaflet called **(enter name of information leaflet here)**?

- No go to question 3
 Yes go to question 2
 Can't remember go to question 3

2. If you looked at the leaflet :

a) Was the leaflet easy to understand?

- No
 Yes
 Can't remember

If you ticked "No" please give further details

.....

b) Was the leaflet helpful?

- No
 Yes
 Can't remember

If you ticked "No" please give further details

.....

c) Was there anything in the leaflet that you found incorrect?

- No
 Yes
 Can't remember

If you ticked "Yes" please give further details

.....

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

.....

INPATIENT QUESTIONNAIRE

Hospice Code

3a. While you were in (enter name of hospice here), did 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 staff involved in your care explain what they were doing?

- Never
- Some of the time
- Most of the time
- Always

4. Overall 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 further comments regarding this?

.....

5. Overall how satisfied were you with your involvement in planning your care?

- Very dissatisfied
- Dissatisfied
- Satisfied
- Very Satisfied

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

.....

6. Overall, 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 given

Is there any way of making 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

INPATIENT QUESTIONNAIRE

Hospice Code

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 courtesy?

- Never
- Some of the time
- Most of the time
- Always

11. Did you feel your privacy was respected e.g. when being examined or during discussions with staff

- Never
- Some of the time
- Most of the time
- Always

12. Were you aware of what to do if you wanted to make a complaint?

- No
- Yes

13. Please rate the following by circling your response: (1 =poor to 5 = excellent)

| | | | | | |
|---|---|---|---|---|---|
| 13a The cleanliness of the premises | 1 | 2 | 3 | 4 | 5 |
| 13b The quality of the catering | 1 | 2 | 3 | 4 | 5 |
| 13c Access to food other than at set meal times | 1 | 2 | 3 | 4 | 5 |
| 13d The general environment/surroundings | 1 | 2 | 3 | 4 | 5 |

Do you have any further comments ?

.....
.....

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

- No
- Yes
- Can't remember

INPATIENT QUESTIONNAIRE
Hospice Code

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

- Never
- Some of the time
- Most of the time
- Always
- Did not need to call for assistance

15. Do you have any further comments or suggestions to help us in the further development of our services? (please write below)

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

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

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

Please return the completed questionnaire in the pre paid envelope provided or directly to :
Charlotte Hastie, Centre for Health Services, George Allen Wing, University of Kent ,
Kent, CT2 7NF

Anonymous results of this questionnaire and any actions it has prompted will be available (enter details as appropriate for your hospice)

Thank you again for your help.

Please call (enter details of inpatient clinical manager here) if you wish to contact (enter name of hospice here) with any concerns regarding your care.

Appendix C

HTH Survey Final returns 15th April 2005

| Hospice Name | Inpatient Services | Day Care Services | Total |
|---|--------------------|-------------------|-------------|
| Wheatfields Hospice - Leeds | 36 | 43 | 79 |
| St Luke's Kenton Grange Hospice - Middlesex | 27 | 50 | 77 |
| Myton Hamlet Hospice - Warwick | 30 | 9 | 39 |
| Marie Curie Cancer Care - Tyne | 38 | 25 | 63 |
| Willow Wood Hospice - Lyme | 8 | 30 | 38 |
| South Bucks Hospice - High Wycombe | N/A | 25 | 25 |
| Greenwich and Bexley Cottage Hospice | 15 | 12 | 27 |
| Pendleside Hospice _Burnley | 14 | 15 | 29 |
| St Luke's Hospice - Sheffield | 51 | 59 | 110 |
| Eden Valley Hospice - Carlisle | 17 | 18 | 35 |
| Oakhaven Hospice - Hampshire | 4 | 17 | 21 |
| Blythe House - Derbyshire | N/A | 27 | 27 |
| Bolton Hospice | 37 | 32 | 69 |
| Cotswold Care Hospice - Stroud | N/A | 41 | 41 |
| Dorothy House Hospice Care - Bradford-on-Avon | 35 | 46 | 81 |
| East Cheshire Hospice - Macclesfield | 10 | 22 | 32 |
| Fairhavens - Essex | 41 | 0 | 41 |
| Halton Haven Hospice - Runcorn | 8 | 13 | 21 |
| Marie Curie Centre - Belfast | 7 | 3 | 10 |
| Nightingale House Hospice - Wrexham | 23 | 23 | 46 |
| Phyllis Tuckwell Hospice - Farnham | 18 | 44 | 62 |
| Springhill Hospice - Rochdale | 7 | 25 | 32 |
| St Andrew's Hospice - Grimsby | 11 | 8 | 19 |
| St Ann's Hospice - Cheadle | 46 | 46 | 92 |
| St Catherine's Hospice - Preston | 14 | 44 | 58 |
| St Catherine's Hospice - Scarborough | 19 | 35 | 54 |
| St Clare Hospice - Harlow | 14 | 21 | 35 |
| St John's Hospice - Lancaster | 40 | N/A | 40 |
| St Richard's Hospice - Worcester | N/A | 56 | 56 |
| Sue Ryder Care, St John's Hospice - Bedford | 28 | 8 | 36 |
| Wigan and Leigh Hospice | 18 | 32 | 50 |
| Wisdom Hospice - Rochester | 22 | 48 | 70 |
| West Cumbria Hospice at Home - Wokington | N/A | 0 | 0 |
| Marie Curie Hospice - Bradford | 32 | 33 | 65 |
| St Anne's Hospice - Newport | 14 | N/A | 14 |
| Marie Curie Hospice, Warren Pearl - Solihull | 14 | 11 | 25 |
| Marie Curie House - Tiverton | N/A | 16 | 16 |
| Marie Curie - Caterham | 8 | 22 | 30 |
| Marie Curie Hospice - Edenhall | 6 | 32 | 38 |
| Marie Curie Hospice - Fairmile | 11 | 16 | 27 |
| Marie Curie Hospice - Holme Tower | 4 | 8 | 12 |
| Marie Curie Hospice - Hunters Hill | 16 | 10 | 26 |
| Marie Curie Hospice - Liverpool | 7 | 18 | 25 |
| St Michael's Hospice - Hereford | 20 | 26 | 46 |
| St Oswald's Hospice -Tyne | N/A | 32 | 32 |
| Weston Hospice Care - Somerset | 14 | 34 | 48 |
| Pasque Hospice - Luton | 10 | 27 | 37 |
| Pilgrims Hospice in East Kent - Ashford | 59 | 54 | 113 |
| Harris Hospiscare - Pettswood, Kent | N/A | 23 | 23 |
| Southern Area Hospices Services - Co. Down | 9 | 18 | 27 |
| St Kentigern Hospice - North Wales | 12 | 41 | 53 |
| Willowbrook Hospice - Merseyside | 31 | 36 | 67 |
| Highland Hospice - Inverness | 6 | 15 | 21 |
| The Lions Hospice - Gravesend, Kent | 15 | 49 | 64 |
| Total | 926 | 1398 | 2324 |