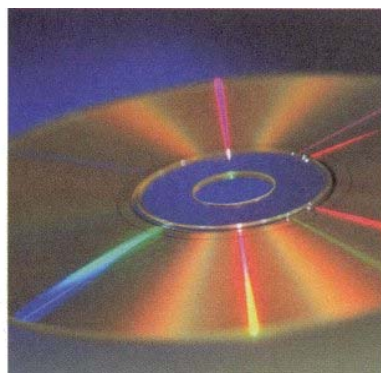
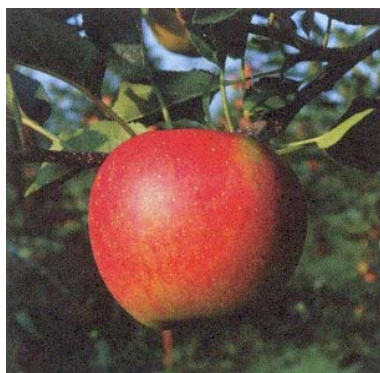




Centre for Health Services Studies

Results of the 2010/2011 Hospice Patient Survey

General Report



Linda Jenkins and Jan Codling

October 2011



Results of the 2010/2011 Hospice Patient Survey

General Report

Linda Jenkins, Centre for Health Services Studies, University of Kent

Jan Codling, Lead for Quality & Audit, St Ann's Hospice, Manchester

© The Centre for Health Services Studies

Commissioned by:

**Help the Hospices, Hospice House, 34-44 Britannia Street, London.
WC1X 9JG**

Help the Hospices is the National Charity for the hospice movement
(registered charity No 1014851).

Further copies can be obtained from:

Librarian
Centre for Health Services Studies
George Allen Wing
University of Kent
Canterbury
Kent CT2 7NF

Tel. 01227 824057
Fax. 01227 827868
chssenquiries@kent.ac.uk
<http://www.kent.ac.uk/chss>

Centre for Health Services Studies

CHSS is one of three research units of the University of Kent's School of Social Policy, Sociology and Social Research and contributed to the school's recent Research Assessment Exercise 6* rating. This puts 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 is directed by Professor Andy Alaszewski and draws together a wide range of research and disciplinary expertise, including health and social policy, medical sociology, public health and epidemiology, elderly medicine, primary care, physiotherapy, statistical and information analysis. CHSS supports research in the NHS in Kent and has a programme of national and international health services research. While CHSS undertakes research in a wide range of health and health care topics, its main research programmes comprise-

- Risk and health care
- Health and social care of vulnerable adults
- Public health and public policy
- Injury prevention and surveillance
- Ethnicity and health care

Researchers in the Centre attract funding of nearly £1 million per year from a diverse range of funders including the ESRC, MRC, Department of Health, NHS Health Trusts and the European Commission.

For further details about the work of the Centre please contact:

Peta Hampshire
Administrator
Centre for Health Services Studies
George Allen Wing
University of Kent
Canterbury
Kent CT2 7NF

Tel: 01227 824057
E-mail: p.r.hampshire@kent.ac.uk
Fax: 01227 827868
www.kent.ac.uk/chss

Contents

Acknowledgements

	Page
Executive Summary	1
1. Introduction	3
2. Methods	4
3. Results: Daycare	7
3.1 Individual Hospice Daycare Results (not applicable)	7
3.2 Benchmark Daycare Results (13 benchmark hospices)	7
3.3 Average Daycare Results Overall (all 37 hospices)	25
3.4 Daycare Textual Comments (all 37 hospices)	29
4. Results: Inpatient	36
4.1 Individual Hospice Inpatient Results (not applicable)	36
4.2 Benchmark Inpatient Results (4 benchmark hospices)	36
4.3 Average Inpatient Results Overall (all 35 hospices)	52
4.4 Inpatient Textual Comments (all 35 hospices)	55
5. Summary of Findings	61
6. Considerations for the Future	63

Appendices :

- A - Daycare questionnaire
- B - Inpatient questionnaire
- C - Questionnaire amendments
- D - Response statistics – All Help the Hospices Patient Surveys
- E - Questionnaire returns spreadsheet

Acknowledgements

We would like to thank Help the Hospices and the 39 hospices who funded the study and agreed to take part in the survey, to whom we are grateful. Particular thanks go to all the patients who answered our questions about their experience of hospice services.

We are also grateful to Amber Morgan at Help the Hospices for her administrative support throughout the survey period.

Executive Summary

- The 2010/11 survey is the fourth in a series of surveys on patient satisfaction with inpatient and daycare services carried out by Help the Hospices and the Centre for Health Services Studies at the University of Kent, with previous surveys being completed in 2004/05, 2006/07 and 2008/09. All hospices across the UK were invited to take part in the 2010/11 Patient Survey and 39 hospices participated between September 2010 and May 2011.
- The Help the Hospices Patient Survey Group discussed and agreed amendments to keep the survey up to date and add topics of current interest to hospices. For example, new questions were introduced on whether patients had the opportunity to discuss end of life care, and whether staff tried to meet patients' religious/spiritual needs. The 2010/11 survey also asked about staff washing their hands and noise levels in hospices. There were new questions for inpatients about hospice visiting hours and the information they were given on medicines when leaving the hospice. These replaced questions that were no longer seen as a priority.
- The method of data collection was a self-completion questionnaire, with one questionnaire for adult users of daycare services and another for inpatient services. Each hospice distributed a questionnaire and an accompanying information letter to inpatients at discharge and to daycare patients at discharge or after two months of attending daycare. The survey included respite patients, those being discharged for terminal care at home, and readmissions even though the latter group may have been given the opportunity to complete the questionnaire more than once.
- There were 1984 replies, 1150 from daycare users and 834 from inpatients. Response rates were 62% for daycare patients, and 45% for inpatients, which was an increase on the last survey in response from inpatients. Response rates were more reliable in 2010/11 as, for the first time, all hospices kept records of the questionnaires handed out. Results are shown separately for the two services, and as well as the figures for all hospices, the report gives the results for hospices that achieved the benchmark figure of 40 responses.
- Results in 2010/11 were broadly similar to the previous survey with the majority of patients expressing high levels of satisfaction with and speaking very highly of the services they received.
- Regarding the information hospices supply their patients, around two thirds of the patients were aware of a leaflet or information booklet (although the proportion was lower for inpatients in the four benchmark hospices). The proportion of daycare patients having seen information has gone up since the last survey. Those that received written information found it helpful and easy to read, and this was especially the case for daycare patients. A number of comments were made about the information, such as to give more detail about hospice routines and activities, about the sources of funding for hospices, and some said the hospice undersold the facilities they offered. Less than half said they had seen notices or posters telling them how to make a complaint, but many felt this did not matter as they had no reason to complain.
- Daycare patients were asked how anxious they were at the beginning and end of their first visit, and this showed anxiety levels dissipating by the end of their first attendance.
- Daycare patients were asked about the transport service, which was used by 70% (fewer users than found in the last survey). Punctuality, comfort and safety of hospice transport were rated as excellent or good by the great majority, but there was wide variation in the results for individual hospices. Comments highlighted some problems with the driving, the comfort of the journey and some issues with timing of the transport.

- Respondents were overwhelmingly positive in their comments about staff, and the caring role that the hospices as a whole provided. On the specific question of whether staff introduced themselves to patients and explained what they were doing, there were improvements on the previous survey, particularly for inpatients. Patients in both services had high levels of confidence in the staff. Inpatients were aware of how to call for help and were very satisfied with the response. Many of the daycare patients felt there were always enough staff or volunteers around to offer help if needed.
- More inpatients reported the highest level of satisfaction with their involvement in planning their care compared to than daycare patients for whom satisfaction has been declining (only 56% daycare patients were very satisfied compared to 74% in 2006/7 and 60% in 2008/9). Comments showed that some patients would like more involvement and information about their care options. Patients were divided on whether they had had the opportunity to discuss end of life care, with half the inpatients and a smaller proportion of daycare patients saying they had been given the chance. The appropriate timing of this was clearly an issue for some people.
- Patients usually felt able to ask questions when they wanted to, with higher satisfaction levels being reported by inpatients. The majority had no trouble understanding explanations about treatment and care that they were given, and very few inpatients had any problem understanding how to take medicines when they left the hospice.
- There was a more mixed response to whether staff had made an effort to meet patients' religious and spiritual needs, with some commenting that they did not have such needs. On the other hand privacy, dignity and respect were highly rated for both daycare and inpatients. Despite this, inpatient comments indicated some privacy problems.
- Both inpatients and daycare patients rated hospices highly on cleanliness, staff hand-washing and for the general environment, with inpatient ratings again being slightly higher than those of daycare patients. However, compared to the previous survey, there has been a decline in the rating of the hospice environment by daycare patients. Inpatients were more likely to say they were bothered by noise, and the comments bore out a number of significant causes. Inpatients were overwhelmingly happy with the arrangements for their visitors.
- The quality and choice of the food for all, and the out of hours access to food for inpatients were satisfactory. There was wide variation between individual hospices in the rating of catering. The available activities were less highly rated and the comments highlighted different individual preferences and how hard it would be to cater for them all.
- It is recommended that participating hospices develop their own action plans where there is scope for improvement, identified from their individual results.

1. Introduction

Welcome to the fourth Hospice Patient Survey coordinated by Help the Hospices in conjunction with the Centre for Health Services Studies at the University of Kent. The report details the findings for the 39 Hospices that participated in the survey between 1st September 2010 and 30th April 2011.

Since its original conception in 2003, the Hospice Patient Survey has evolved, incorporating information from two pilot studies and feedback from many stakeholders, including hospices and service users. The investment by all involved in its development and use reflects the importance they place on hearing how people experience care including that provided by hospices. Whilst it is widely acknowledged that hospices provide very high quality care, there is always room for improvement and this survey offers one way to identify such opportunities. Listening to the views of people who use our services as a basis for service improvement is at the heart of high quality provision.

The design of surveys to hear patient views is not straightforward and we are grateful to our colleagues in the Help the Hospices Patient Survey Group for their advice on survey methods and their help in identifying emerging priorities. We have sought the views of hospice service users to ensure clarity and ease of completion of the questionnaire and are delighted to have achieved the plain English "Crystal Mark" for the last two versions of the survey. The questionnaire is anonymous – incorporating questions relating to information giving, staff attitudes, involvement in care planning, confidence in staff, privacy and courtesy, catering and hygiene, and awareness of the process for making a complaint. The most recent version has included additional questions on hand hygiene, noise levels, advance care planning, information on medications at discharge and hospice visiting arrangements to reflect new areas of interest or concern.

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

This report of the findings can be used as part of the evidence of compliance with Essential Standards of Quality and Safety – Outcome 1 (Care Quality Commission March 2010) and also gives the opportunity for hospices where 40 or more questionnaires are returned from a service, to compare their results with other hospices, in a manner which is statistically valid.

We hope that readers find it useful and that it helps participants to agree an action plan as required.

Jan Codling
Chair – Help the Hospices Patient Survey Group
Lead for Quality & Audit , St Ann's Hospices, Manchester.

Heather Richardson, National Clinical Lead, Help the Hospices, London

2. Methods

The 2010/11 survey is the fourth in a series of surveys on patient satisfaction with inpatient and daycare services carried out by Help the Hospices and the Centre for Health Services Studies, with previous surveys being carried out in 2004/05, 2006/07 and 2008/09. As in the previous surveys the method of data collection was by self-completion questionnaire, as this enabled the collection of a large number of responses at relatively low cost. One questionnaire was designed for the evaluation of daycare services and another for evaluation of inpatient services for adults (Appendix A and B). Amendments were made to the survey to keep up to date with current topics of interest for hospices. The changes to the questionnaires are outlined in Appendix C.

All hospices across the UK were invited by letter to take part in the 2010/11 Patient Survey. 39 hospices participated in the survey, with 37 of these hospices participating in daycare and 35 in the inpatient survey. Most hospices participated in both surveys, with the remainder surveying one service. This time 33 hospices distributed questionnaires to both daycare services and inpatient services, 4 distributed questionnaires to patients using daycare services only, and 2 hospices distributed to inpatient services only. The overall number of hospices participating in both services and in daycare was down on previous surveys but this was compensated by an increase in the average number of returned questionnaires.

The Help the Hospices Patient Survey Group discussed and agreed a range of amendments to the 2010/11 questionnaires. New questions were introduced about having the opportunity to discuss care at end of life (advanced care planning), and whether staff made efforts to meet religious and spiritual needs. These replaced less clearly worded questions on similar themes. New questions were also added to ask if staff washed their hands, and if patients were troubled by a noisy environment. There were new questions for inpatients about the visiting arrangements and if explanations about medicines after discharge were clear. In both daycare and inpatient questionnaires there were minor changes to question wording and layout of response options. Appendix C maps old questions to new and shows where all the changes were.

All participating hospices were invited to a survey launch meeting where they could learn about the survey process, ask any questions, and learn from each others' experience with the patient survey in previous years. Survey materials were distributed at the same time as the launch. Each hospice was given a guidance sheet with detailed instructions of appropriate procedures, including start and end date, inclusion and exclusion criteria, informing patients of the survey and how to return it. When distributing the questionnaires, hospice staff were asked to reassure patients that the survey was anonymous and the staff giving the care would not see the completed questionnaire; and to say that patients were under no pressure to complete the survey and it would have no effect on their future care.

The survey was distributed to all adult patients in the participating hospices using inpatient and/or daycare services. This included respite patients and patients being discharged for terminal care at home, as their condition may unexpectedly change and they may still appreciate the opportunity to express their views. Readmissions were also given the opportunity to complete the questionnaire, even if this meant they completed it a second time. Carers of patients were allowed to complete the survey on behalf of patients if required, however the views recorded had to be the views of the patient and not those of the carer. Hospices themselves were responsible for handing out the survey, and it is possible that some patients may not have been given a questionnaire based on clinical judgement due to reasons of altered consciousness or altered cognitive ability of the patient.

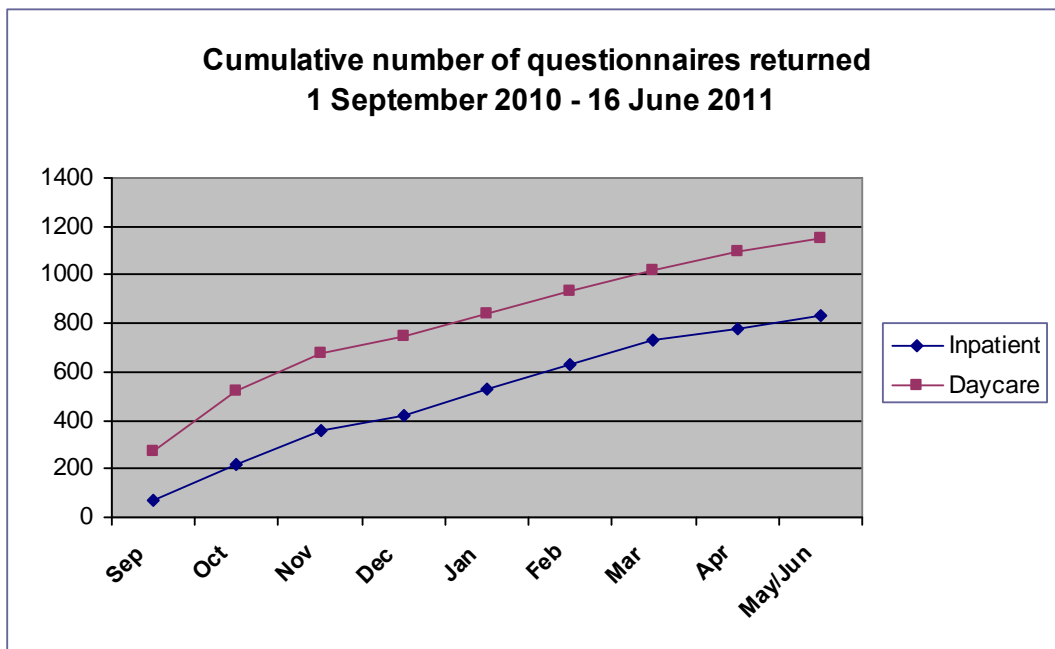
Participating hospices distributed questionnaires and an accompanying information letter to their own patients by printing off electronic copies and distributing them to inpatients at discharge and to daycare patients at discharge or after two months of attending daycare. The benefit of individual hospices printing off electronic copies was that hospices could tailor the instructions and style to fit their hospice and it enabled them to re-format the survey as required to help patients with visual-impairments. It also allowed hospices to personalise the questionnaire by

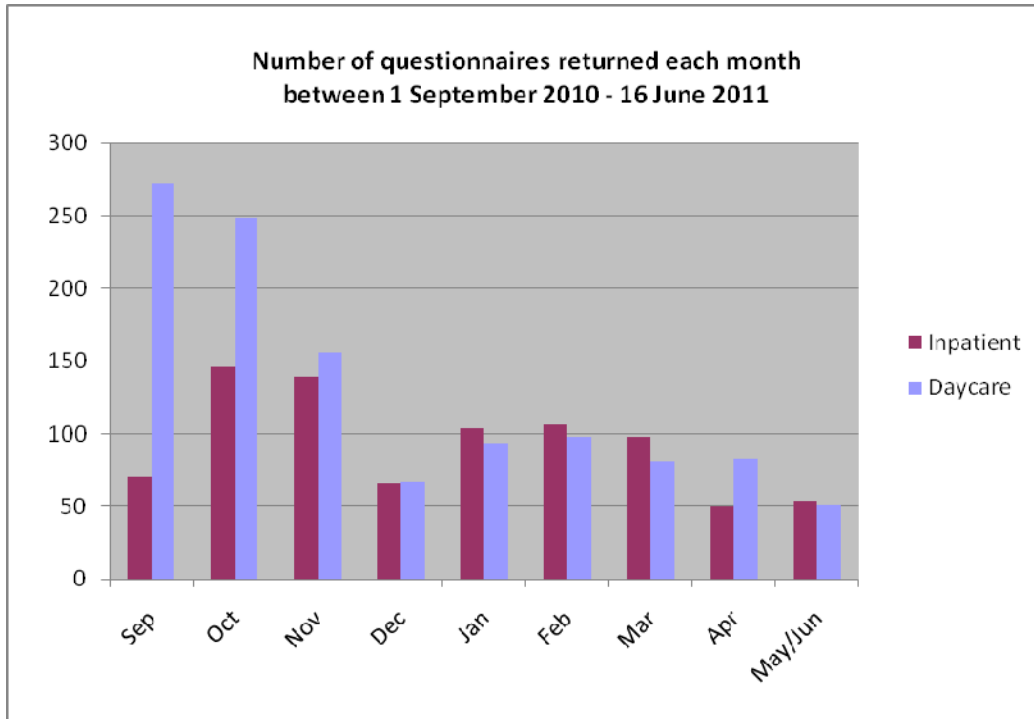
having it on different coloured paper, with their logo, and tailoring certain information questions where indicated e.g. by including the name of the hospice, and a leaflet or booklet providing written information about their services. In order to ensure validity and prevent any bias in the answers given through inhibited responses, patients were encouraged to fill in the questionnaires at home rather than 'on the spot'.

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

Following experiences of the previous patient surveys the time frame for distribution and return of questionnaires was scheduled for eight months, between September 2010 and April 2011. Each month during this period, hospices were emailed to inform them of the number of responses the survey administrators (CHSS) had received, and hospices provided the number of surveys they had handed out. A target of 40 completed questionnaires returned from one or both services was considered enough as a 'benchmark' figure. This figure was decided upon during the course of the 2004/05 survey as the vast majority of hospices found it difficult reaching the previous benchmark threshold of 50 responses. Although it was encouraged for statistical reasons, the ability to achieve the benchmark depended on the size of the hospices involved. Smaller hospices found it more difficult to achieve the benchmark of 40 or more completed questionnaires, as they give care to a more limited number of patients, whereas larger hospices stood a better chance of reaching the benchmarking figure. It was therefore not compulsory for all the hospices taking part to reach the benchmark.

The tables below show the frequency at which the questionnaires were returned each month over the fieldwork period. Questionnaires were accepted up until mid June to allow for return of questionnaires distributed in late April at the end of the distribution period. As expected the number of questionnaires returned was lower for inpatient services (834) compared to daycare services (1150), probably due to the lower number of patients using these services. Compared to the previous survey fewer hospices took part, but in 2010/11 the average number of responses per hospice increased and more hospices met the benchmark for daycare services (Appendix D).





Overall the rate at which questionnaires were returned was reasonably steady for both daycare and inpatients, apart from a good start and a slight slowing down over Christmas. A decrease in returns for daycare over time is normally expected due to the reducing number of patients who fit the criteria (as time passes many daycare patients regularly using the service will have already received the questionnaire), but this was not apparent in 2010/11. For the actual numbers returned by individual participating hospices see Appendix E. As mentioned previously the number of responses received can depend on the size of the hospice, information on the size of individual hospice daycare and inpatient units is available in the annual UK Hospice and Palliative Care Directory.¹

As an indicator of potential bias in surveys it is important to know what percentage of questionnaires handed out are actually completed. In previous years not all hospices had kept records of the number of questionnaires they had distributed during the fieldwork period, so information on response rates was incomplete. This year all hospices kept records enabling response rates to be calculated (however for two daycare services and two inpatient services the number of surveys handed out was clearly incomplete, so these were not included in response rate averages). The overall response rate for the survey was 62% for daycare based on 35 hospices and 45% for inpatient based on 33 hospices. These response rates are similar to previous surveys, but the figures are much more robust this time as in previous years only 50% of hospices had provided the necessary information (Appendix D).

The collected data was entered and analysed, generating descriptive statistics, using SPSS software version 19 (Statistical Package for the Social Sciences). Open ended and textual comments were typed in verbatim and analysed separately using Microsoft Excel.

¹ Help the Hospices. *Hospice and Palliative Care Directory – UK and Ireland*. London: Help the Hospices. The directory is also available to search online at: <http://www.helpthehospices.org.uk/our-services/information-service/uk-hospice-and-palliative-care-services/?locale=en> 18/10/11

3. Results: Daycare

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

3.1 Individual Hospice Daycare Results

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

3.2 Benchmark Daycare Results (13 benchmark hospices)

Thirteen hospices reached the benchmark figure of a minimum of 40 returned daycare questionnaires and are included in these benchmark results representing 597 patient views. This section of the report gives an overview of the aggregate results of these hospices by presenting the results in tables, charts and in a written commentary of the findings for each area covered by the survey including provision of information about services, anxiety when first visiting daycare, use of transport, staff communication and care, user involvement and understanding, views of users on support and respect they receive from staff, views on facilities and services.

The results, in table form, report the average patient responses (counts and percentages) from all thirteen hospices aggregated together. The range of aggregated results (minimum and maximum) of the benchmark hospices are also reported, showing the result for the lowest average benchmark hospice and the result for the highest average benchmark hospice for each question. The average results displayed in these tables are then reported visually in a bar-chart for each question. One of the hospices meeting the benchmark had made a photocopying error which increased the number of missing answers for Q1d - Q5, Q10 - Q13 and Q18 - Q20. This hospice was treated as an outlier so does not appear in the minimum and maximum values for these questions.

The benchmark results for daycare are similar to the previous survey in 2008/09, and any notable differences (of +/-5% or more) are reported in the written commentary. However different groups of hospices reaching the benchmark in both surveys make it difficult to interpret how meaningful such comparisons of similarities or differences are. Thirteen hospices achieved the daycare benchmark this year compared to only nine in the last survey. Only five out of the thirteen hospices in this year's benchmark results also achieved the daycare benchmark in the 2008/09 survey.

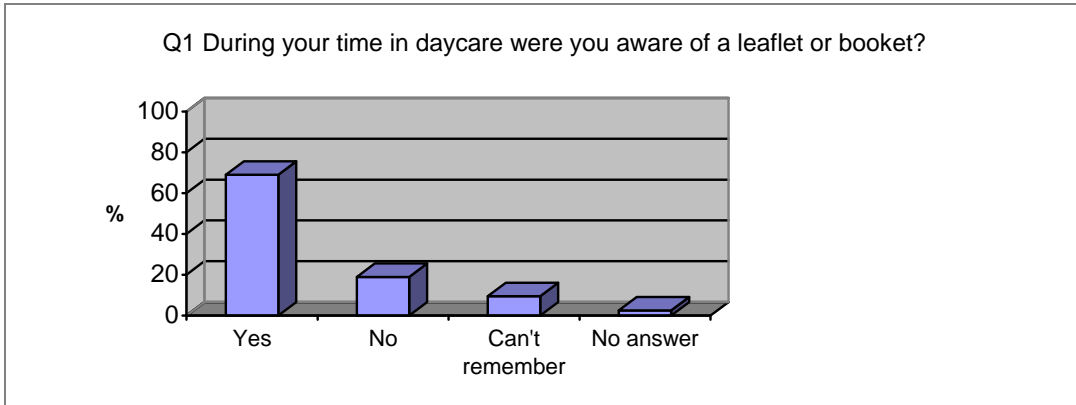
Provision of information about daycare services

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

Over two thirds (69%) of daycare patients said they were aware of an information leaflet or booklet, which is 14% more than the last survey. The variation in awareness of such a leaflet or booklet in the benchmark hospices has reduced, but still ranged from under half of the respondents indicating they were aware of information leaflets or booklets in one hospice, up to nearly 80% in another. This may indicate different usage of booklets and leaflets as an information tool within the benchmark hospices.

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

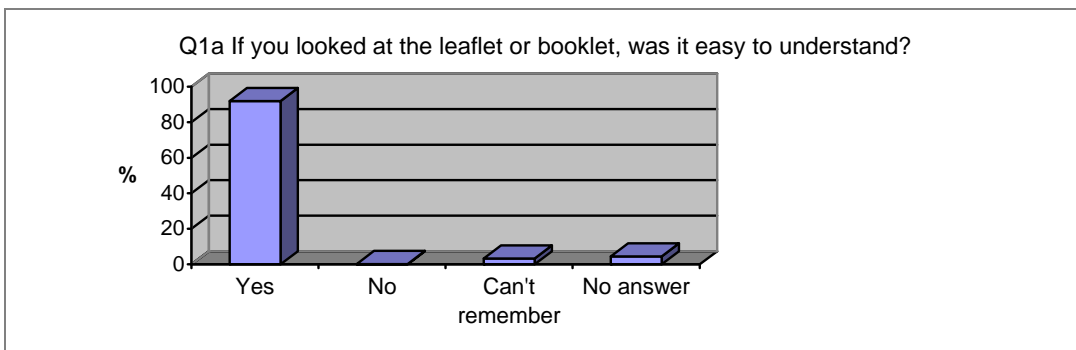
	N	Average (%)	Range (%)
Yes	412	69.0	44.9 – 79.2
No	113	18.9	6.3 – 36.7
Can't remember	57	9.5	0.0 – 14.3
No answer	15	2.5	0.0 – 6.1
Total	597	100	



Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on daycare services, with the vast majority of patients who had looked at the leaflet reporting that it was easy to understand (92%) and that it included information that was helpful to them (92%) which was very similar to previous surveys. One or two patients said that they felt it was hard to understand or thought it was unhelpful. 4% couldn't remember if the leaflet or booklet was helpful or not. A few people said they had not looked at it.

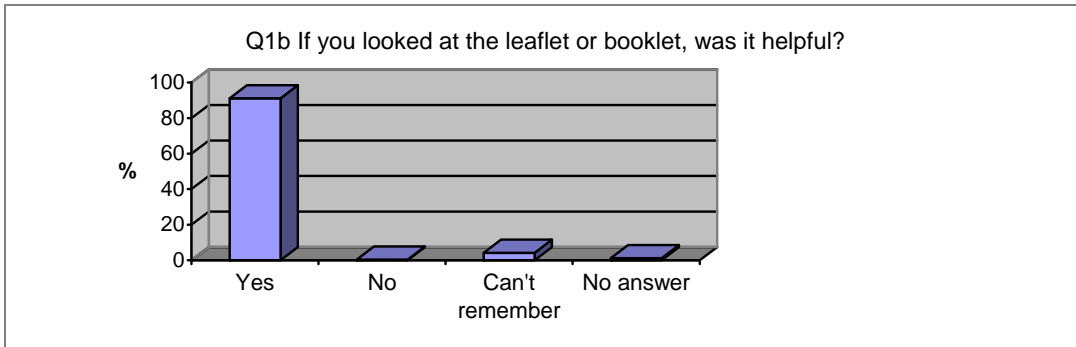
Q1a If you looked at the leaflet or booklet, was it easy to understand?

	N	Average (%)	Range (%)
Yes	386	91.9	85.7 – 92.3
No	1	0.2	0.0 – 3.8
Can't remember	14	3.3	0.0 – 9.7
No answer	19	4.5	0.0 – 10.7
Total	420	100	
Did not look at the leaflet or booklet: 7			
Not applicable: 170			



Q1b If you looked at the leaflet or booklet, was it helpful?

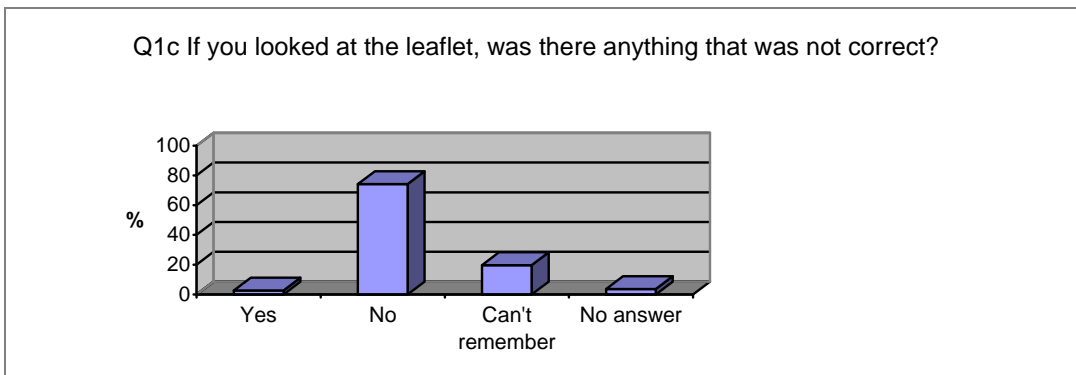
	N	Average (%)	Range (%)
Yes	388	91.9	83.9 – 95.5
No	2	0.3	0.0 – 3.3
Can't remember	25	4.2	0.0 – 16.1
No answer	7	1.2	0.0 – 7.1
Total	422	100	
Did not look at the leaflet or booklet: 5			
Not applicable: 170			



Only 3%, equating to 11 patients, said that they found something to be incorrect in the leaflet or booklet. However 20% said they couldn't remember if they found anything that was incorrect. Only 2% of patients who had looked at the leaflet made comments or suggestions about improvements to the leaflet (for comments on incorrect information and suggestions of more information to include in the leaflet see the 3.4 textual comments section of this report covering all hospices taking part).

Q1c If you looked at the leaflet or booklet, was there anything that was not correct?

	N	Average (%)	Range (%)
Yes	11	2.6	0.0 – 7.7
No	313	74.2	61.3 – 86.7
Can't remember	83	19.7	3.3 – 32.3
No answer	15	3.6	0.0 – 7.7
Total	422	100	
Did not look at the leaflet or booklet: 5			
Not applicable: 170			

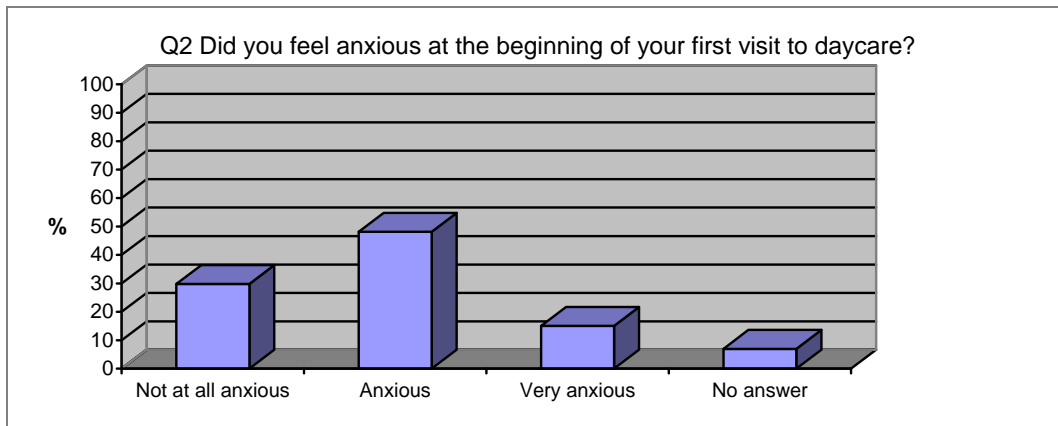


Anxiety on first daycare visit

Respondents were asked about how anxious they felt on their first visit to their daycare hospice. The questions asked were designed to measure the difference in anxiety felt at the beginning of their first visit compared to the anxiety they felt at the end of their first visit. The results show that levels of anxiety at the beginning of the first visit were similar to previous years, with 30% of respondents reporting that they were not at all anxious, nearly half (48%) saying they did feel anxious, and 15% feeling very anxious. (Note that in 2010/11 the survey offered people three options for rating their anxiety compared to the 5-point scale in 2008/09). As in previous years the questions showed that respondents were much less anxious at the end of their first visit, with a high 84% reporting that they were not anxious at all, and hardly anyone (0.5%) reporting that they felt very anxious.

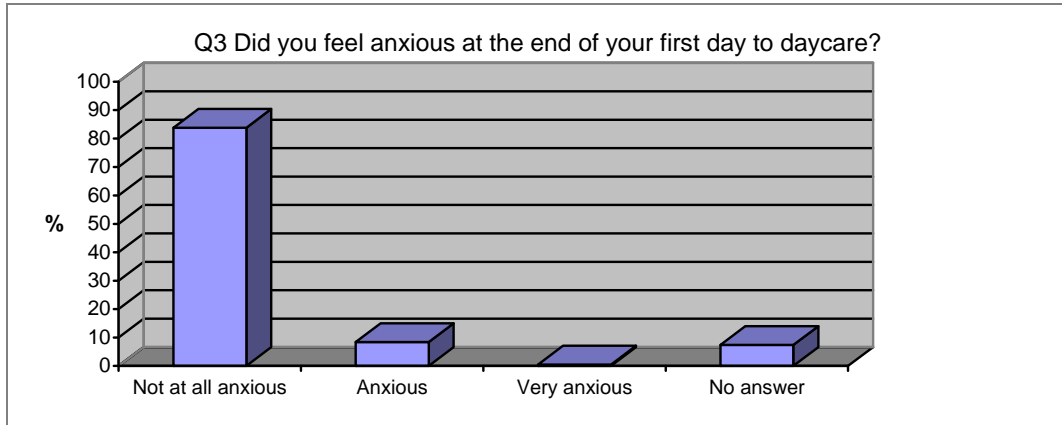
Q2 Did you feel anxious at the beginning of your first visit to daycare?

	N	Average (%)	Range (%)
Not at all anxious	178	29.8	22.5 – 47.5
Anxious	287	48.1	41.7 – 65.0
Very anxious	90	15.1	5.0 – 27.1
No answer	42	7.0	0.0 – 6.7
Total	597	100	



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

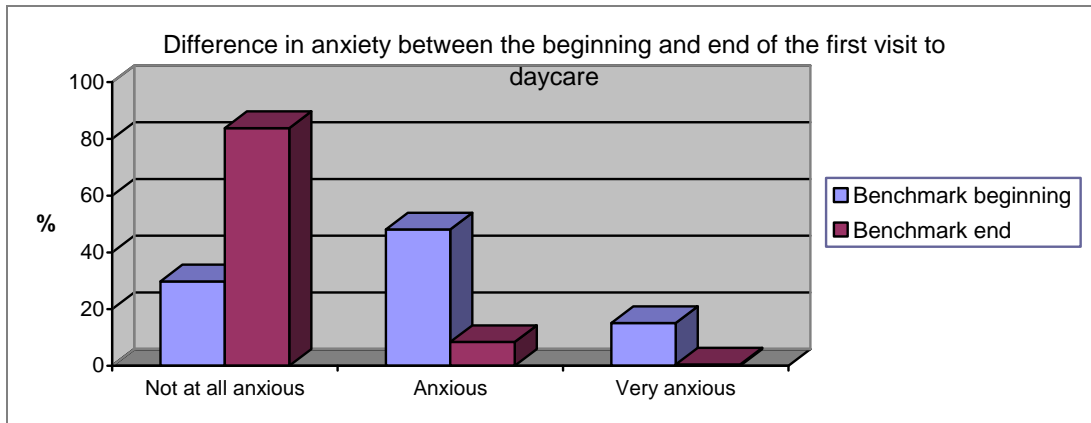
	N	Average (%)	Range (%)
Not at all anxious	500	83.8	81.3 – 98.0
Anxious	50	8.4	0.0 – 16.7
Very anxious	3	0.5	0.0 – 5.0
No answer	44	7.4	0.0 – 6.7
Total	597	100	



Looking more closely at the change in anxiety from the beginning and end of the first visit, the majority of respondents (59%) were less anxious at the end of the visit compared to the beginning. There was only a very small change of 0.5% towards feeling more anxious at the end of the visit compared to the beginning. There was no change in anxiety for 34% of respondents, and these were largely the group who had felt 'not at all anxious' at the beginning of the visit. Results on change in anxiety were not available for 44 respondents (7%) as they did not answer both of the questions on anxiety before and after their first visit to daycare. This is a similar proportion of respondents choosing not to answer these questions compared to the previous survey. Respondents were asked to write down if their hospice could have done anything to help relieve their anxiety on their first visit. Across all hospices 20% or respondents gave an answer and these comments are presented in the 3.4 textual comments section of this report.

Change in anxiety between the beginning and end of the first visit to Daycare (Q2/3)

	N	Average (%)	Range (%)
Less anxious	349	58.5	47.5 – 75.5
No change	201	33.7	24.5 – 50.0
More anxious	3	0.5	0.0 – 2.5
Total	553	100.0	
Missing answers: 44			



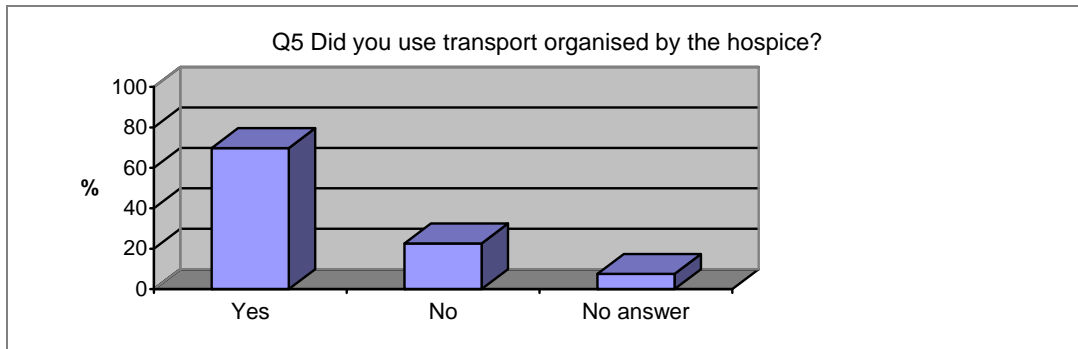
Use of transport by daycare patients

70% of daycare patients reported that they used transport organised by the hospice (ranging between 62% - 88% for the individual benchmark hospices). As in the previous survey the majority who reported using transport organised by their hospice also reported the standard of this service to be excellent. 62% of those who had used

the transport felt the promptness of pick up (i.e. whether they were picked up on time) was excellent compared to 0% who felt it was poor. 65% felt the comfort of the journey was excellent compared to 1% who felt it was poor, and 69% felt the safety aspects were excellent compared to 0% who felt it was poor. The ranges reported below show that there was some variation in the views on hospice transport (a simpler scale was used in 2010/11 making it difficult to compare with 2008/09), but the majority felt the service provided was excellent and few felt it was poor. Further comments made by respondents on hospice transport can be found in the 3.4 textual comments section of this report.

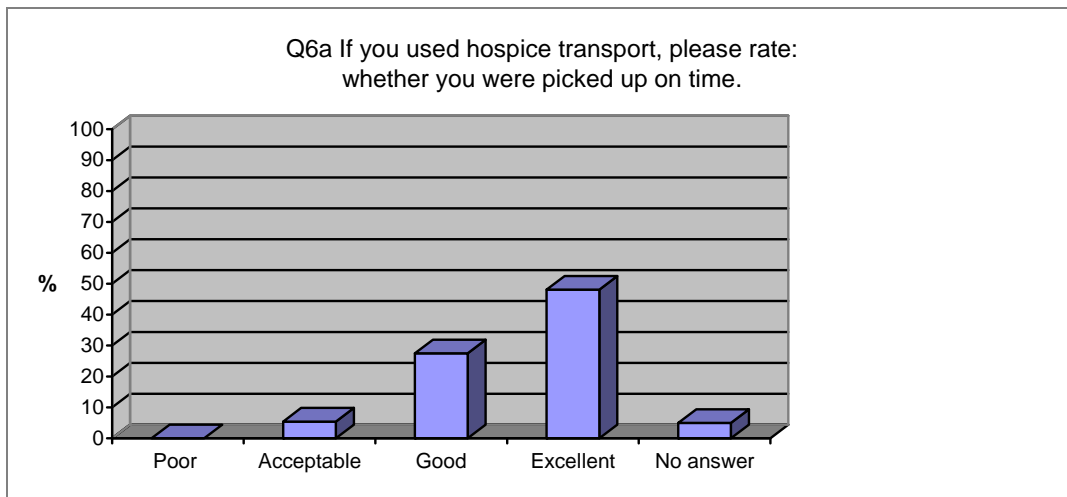
Q5 Did you use transport organised by the hospice?

	N	Average (%)	Range (%)
Yes	417	69.8	62.2 – 87.5
No	135	22.6	12.5 – 37.5
No answer	45	7.5	0.0 – 4.4
Total	597	100	



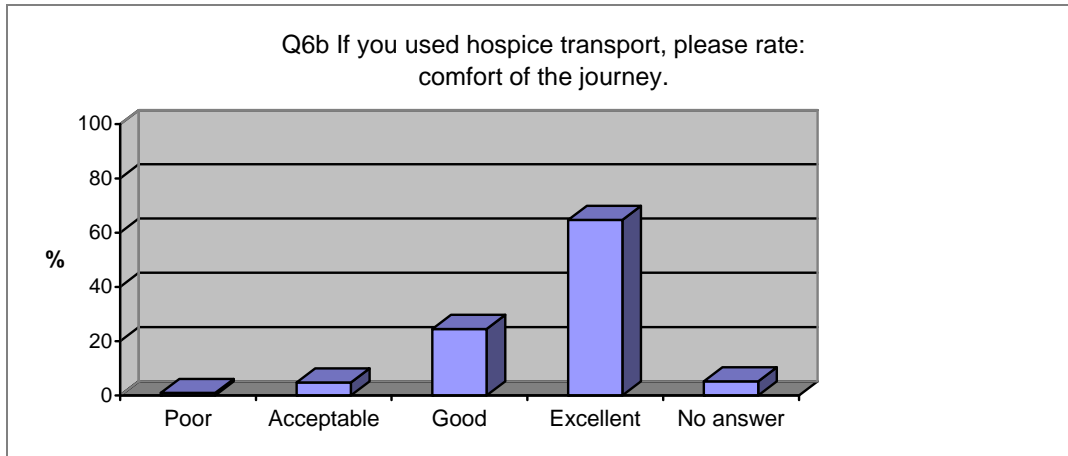
Q6a If you used hospice transport, please rate: whether you were picked up on time.

	N	Average (%)	Range (%)
Poor	0	0.0	0.0 – 0.0
Acceptable	25	5.4	0.0 – 16.7
Good	127	27.5	14.3 – 39.3
Excellent	287	62.1	33.3 – 78.6
No answer	23	5.0	0.0 – 13.3
Total	462	100	
Not applicable: 135			



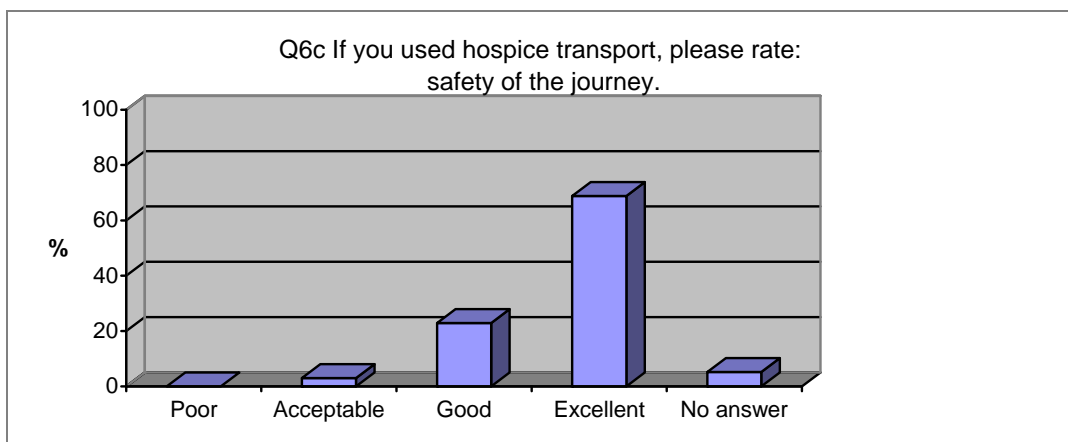
Q6b If you used hospice transport, please rate: comfort of the journey

	N	Average (%)	Range (%)
Poor	4	0.9	0.0 – 3.3
Acceptable	22	4.8	0.0 – 21.1
Good	113	24.5	7.1 – 34.2
Excellent	299	64.7	40.0 – 90.5
No answer	24	5.2	0.0 – 12.5
Total	462	100	
Not applicable: 135			



Q6c If you used hospice transport, please rate: safety of the journey

	N	Average (%)	Range (%)
Poor	0	0.0	0.0 – 0.0
Acceptable	14	3.0	0.0 – 12.0
Good	106	22.9	7.1 – 40.6
Excellent	318	68.8	50.0 – 88.1
No answer	24	5.2	0.0 – 10.0
Total	462	100	
Not applicable: 135			

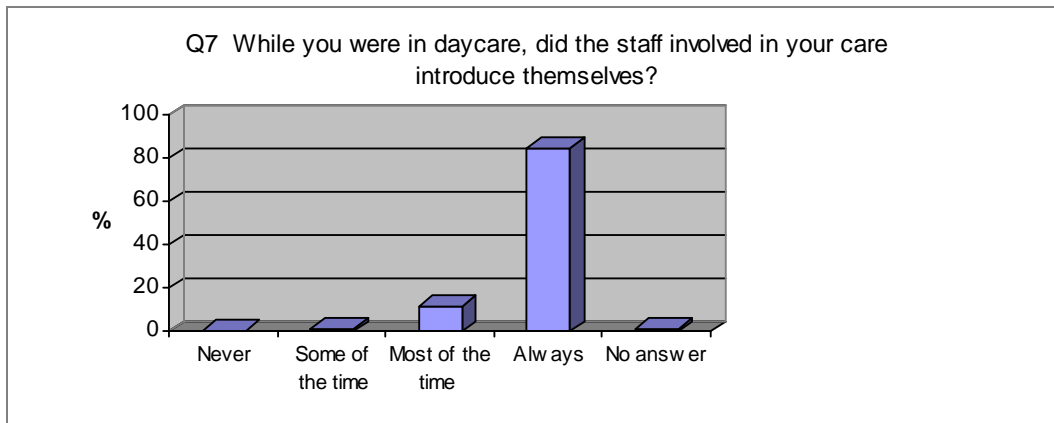


Daycare staff: communication and care

The survey asked patients about the communication and care they had received from staff in daycare. 85% of respondents reported that staff involved in their care always introduced themselves when meeting for the first time. A further 12% said they introduced themselves most of the time and three respondents said that staff had never introduced themselves. As well as an introduction, staff are also regularly explaining what they were doing when caring for patients. 78% reported that staff always explained what they were doing, 17% reported most of the time, and 3 respondents (0.5%) reported that staff had never explained what they were doing. Patients using daycare services were also asked whether they had confidence in the staff who were caring for them overall. The response to this question was very positive with 90% reporting that they always had confidence in the staff caring for them. Not one respondent felt that they 'never' had confidence in the staff. Respondents were invited to make further comments on their confidence in staff, which can be found in the 3.4 textual comments section of this report. Overall respondents were positive about the communication and care received from staff, however there was some variation between individual benchmark hospices with some respondents being less positive than others about the staff.

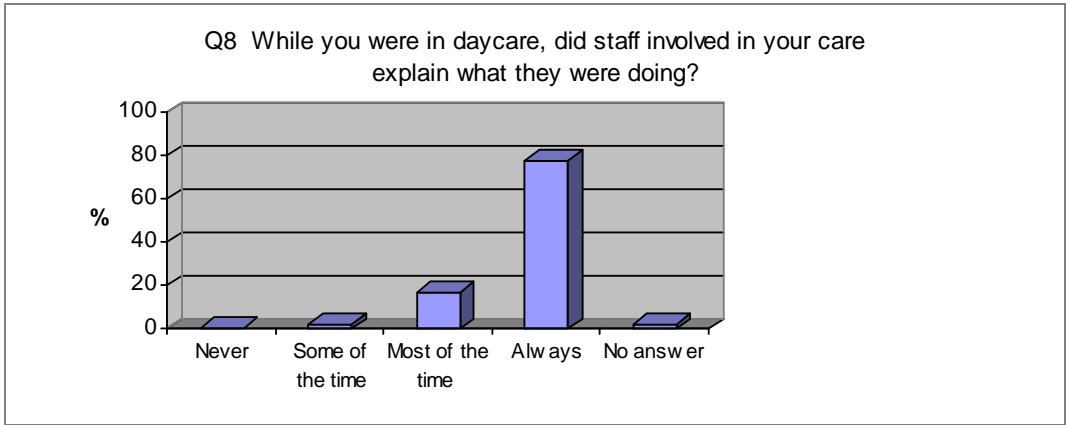
Q7 While you were in daycare, did the staff involved in your care introduce themselves?

	N	Average (%)	Range (%)
Never	3	0.5	0.0 – 4.4
Some of the time	7	1.2	0.0 – 4.4
Most of the time	72	12.1	4.1 – 24.4
Always	505	84.6	66.7 – 92.5
No answer	10	1.7	0.0 – 7.8
Total	597	100	



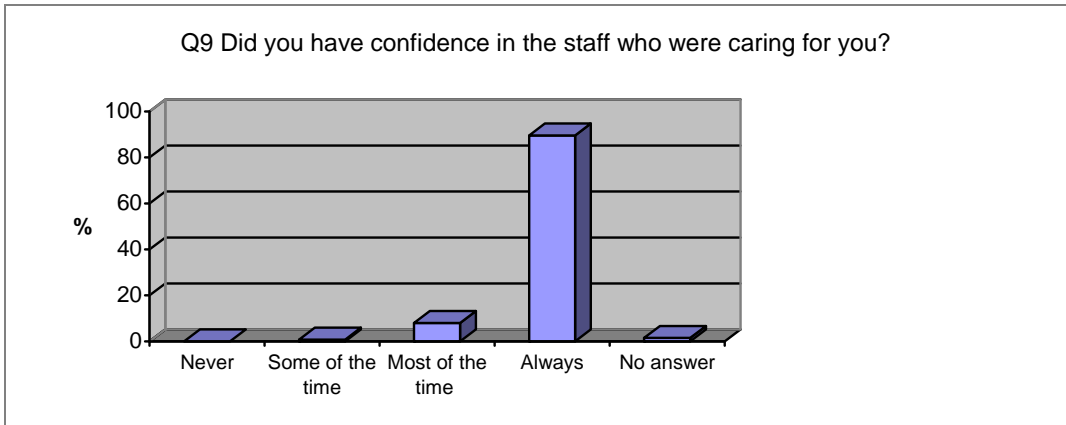
Q8 While you were in daycare, did staff involved in your care explain what they were doing?

	N	Average (%)	Range (%)
Never	3	0.5	0.0 – 2.5
Some of the time	11	1.8	0.0 – 5.0
Most of the time	103	17.3	3.7 – 33.3
Always	467	78.2	60.0 – 95.0
No answer	13	2.2	0.0 – 6.1
Total	597	100	



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

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	5	0.8	0.0 – 5.0
Most of the time	48	8.0	0.0 – 20.0
Always	535	89.6	77.8 – 95.0
No answer	9	1.5	0.0 – 4.0
Total	597	100	

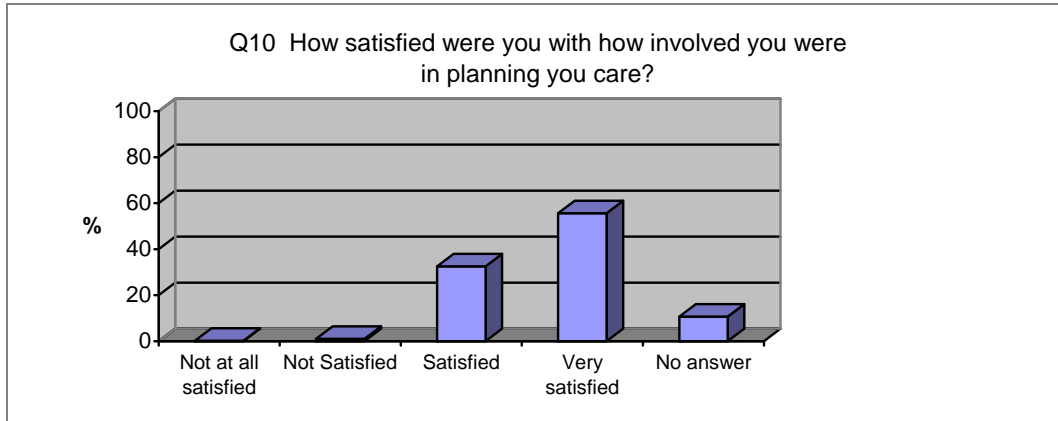


Daycare user involvement and understanding

Patients were asked about their overall satisfaction with their involvement in the planning of their care while in daycare. 56% of respondents were very satisfied, which continues a downward trend (4 percentage points down compared to the last survey). However a third said they were ‘satisfied’ with the level of involvement in their care (similar to the last survey). Only 1% of respondents were either ‘not at all dissatisfied’ or ‘not satisfied’ with their involvement in their care. Some respondents who were either dissatisfied or very dissatisfied made suggestions as to how their hospice could involve them more in the planning of their care (for these suggestions of more information see the 3.4 textual comments sections of this report).

Q10 How satisfied were you with how involved you were in planning your care?

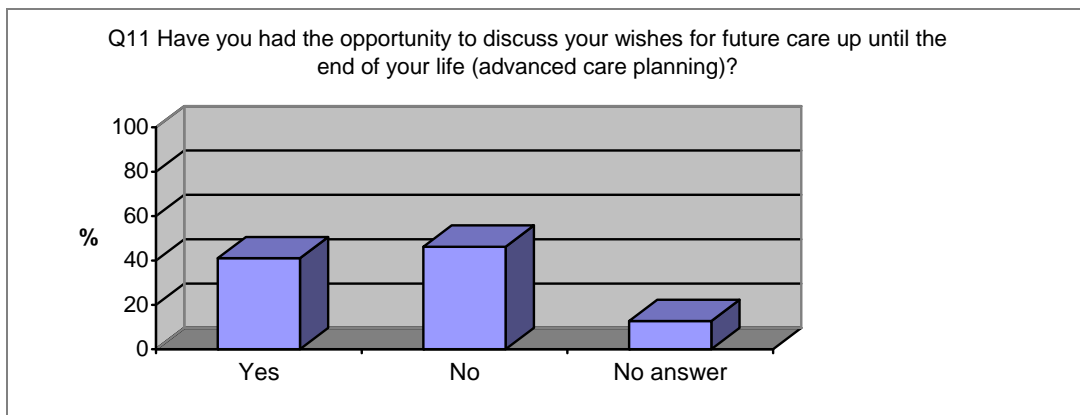
	N	Average (%)	Range (%)
Not at all satisfied	1	0.2	0.0 – 1.9
Not satisfied	6	1.0	0.0 – 5.0
Satisfied	194	32.5	25.0 – 51.1
Very satisfied	332	55.6	44.4 – 68.5
No answer	64	10.7	0.0 – 12.5
Total	597	100	



A new question was included about having the opportunity to discuss wishes for future care up until end of life, in other words asking about advanced care planning. Less than half (41%) felt they had had this opportunity, slightly more (46%) felt they had not and 13% gave no answer.

Q11 Have you had the opportunity to discuss your wishes for future care up until the end of your life (advanced care planning)?

	N	Average (%)	Range (%)
Yes	245	41.0	25.0 – 62.5
No	276	46.2	30.6 – 64.6
No answer	76	12.7	2.2 – 13.5
Total	597	100	

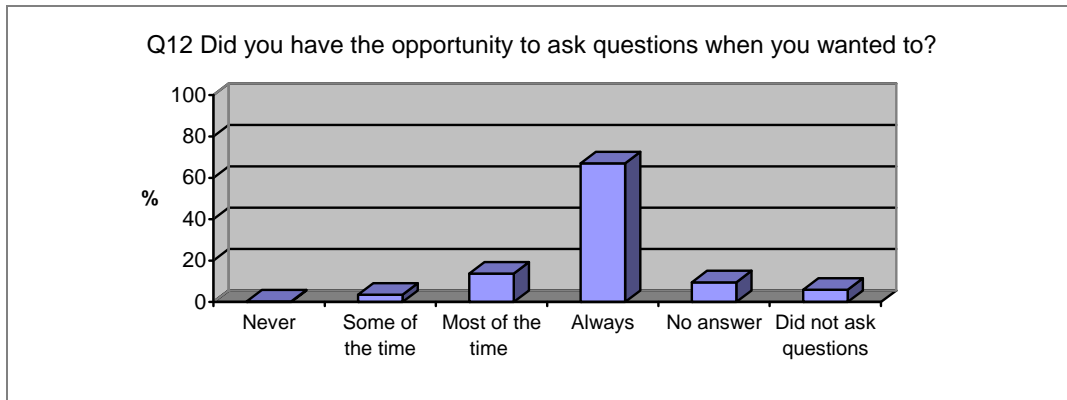


As has been found in previous surveys respondents were positive in their views on the communication with staff more generally. 67% of respondents again felt that they were always given the opportunity to ask questions when they wanted to, and 14% felt this to be true most of the time. Although this was lower than the previous

survey, it could largely be due to people choosing the (new) response option that they did not have any questions.

Q12 Did you have the opportunity to ask questions when you wanted to?

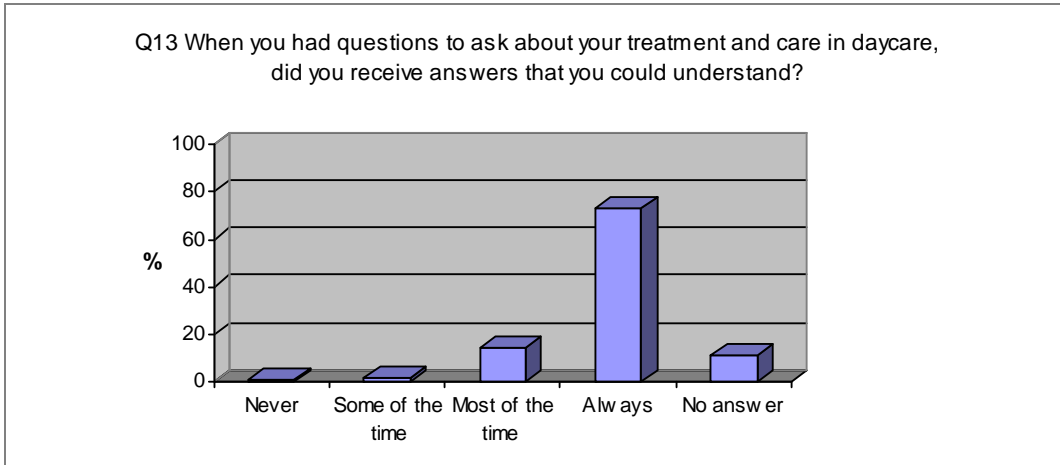
	N	Average (%)	Range (%)
Never	2	0.3	0.0 – 2.5
Some of the time	21	3.5	0.0 – 8.9
Most of the time	82	13.7	2.3 – 22.5
Always	400	67.0	60.0 – 83.7
No answer	57	9.5	0.0 – 10.2
Did not ask any questions	35	5.9	0.0 – 12.2
Total	597	100	



The survey went on to ask users if they understood the explanations given to them about their care while in daycare. The majority of respondents felt that they understood the explanations given to them about their care: 73% felt that they always understood the explanations given, and 14% said they understood most of the time. Two people said that they never understood any of the explanations given to them. Comments were invited on how well explanations were understood (see the 3.4 textual comments sections of this report).

Q13 When you had questions to ask about your treatment and care in daycare, did you receive answers that you could understand?

	N	Average (%)	Range (%)
Never	2	0.4	0.0 – 2.9
Some of the time	9	1.6	0.0 – 5.1
Most of the time	78	14.0	5.1 – 31.0
Always	409	73.2	66.7 – 94.9
No answer	61	10.9	0.0 – 13.0
Total	559	100	
Did not ask any questions: 38			



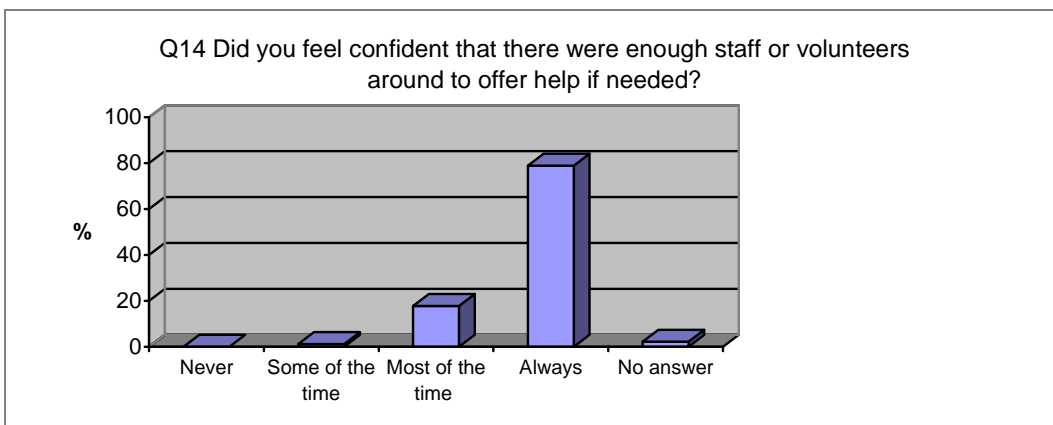
Views of users on the support and courtesy from daycare staff

Patients were asked a number of questions about their views on the support and courtesy from the staff looking after them in daycare. Some of these questions are of a more sensitive nature but were well-completed in the survey.

Patients were asked their view on the number of staff and volunteers working in their hospice. The majority (79%) felt confident that there were always enough staff and volunteers around to offer help if needed, and 18% felt that there were enough most of the time. No one felt there was never enough staff or volunteers available.

Q14 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	7	1.2	0.0 – 2.3
Most of the time	106	17.8	10.0 – 31.1
Always	471	78.9	66.7 – 87.5
No answer	13	2.2	0.0 – 5.0
Total	597	100	

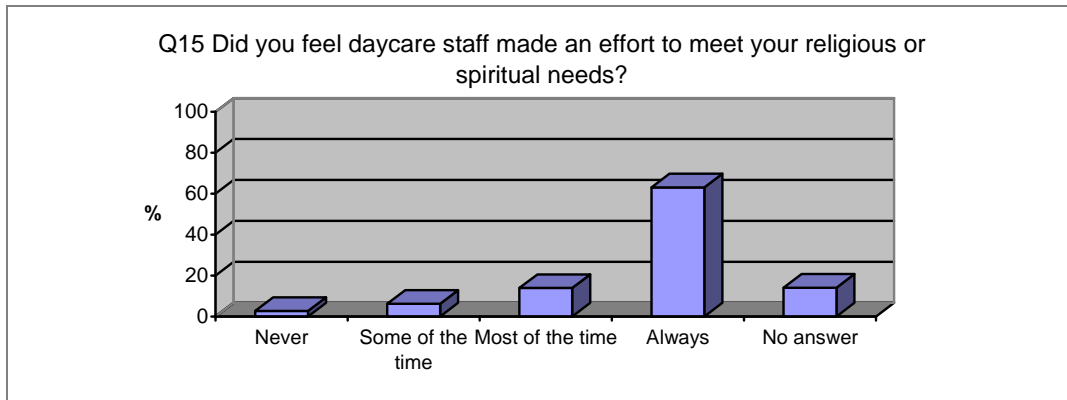


A new question was asked about whether daycare staff made an effort to meet religious or spiritual needs. Nearly two-thirds (63%) felt that staff did this all the time and a further 14% said staff made an effort most of the time. 9% of people felt that staff did not try to meet religious or spiritual needs some of the time or never, and 14% did not answer. The proportion not replying was quite high and may indicate that staff did not go very far in

trying to meet the religious and spiritual needs of these patients, and patients were reluctant to criticise them, however the comments in section 3.4 showed that quite a lot of patients did not want any religious or spiritual support.

Q15 Did you feel daycare staff made an effort to meet your religious or spiritual needs?

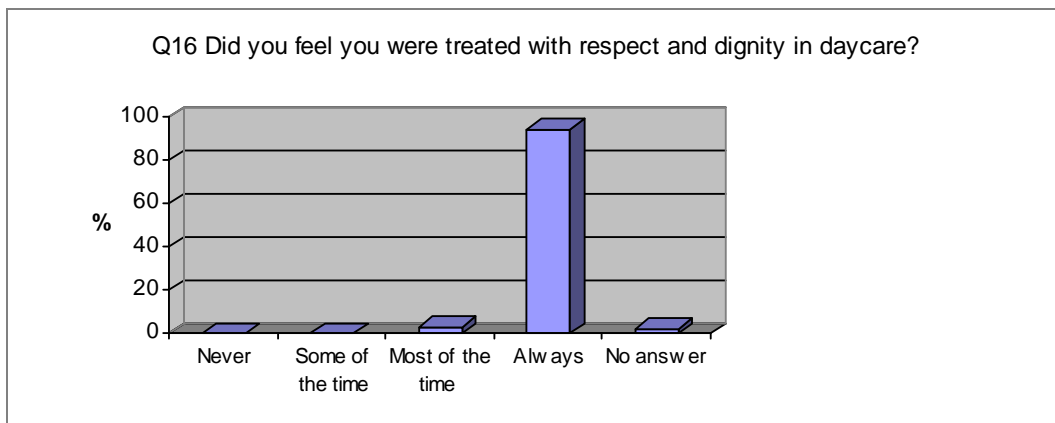
	N	Average (%)	Range (%)
Never	16	2.7	0.0 – 8.3
Some of the time	37	6.2	0.0 – 15.6
Most of the time	83	13.9	8.2 – 25.0
Always	377	63.1	44.4 – 83.7
No answer	84	14.1	4.7 – 25.0
Total	597	100	



The vast majority of daycare patients (95%) felt they were always treated with respect, and 88% felt that their privacy needs were always met. This was an improved response as the figures were three percentage points higher than the previous survey. No-one said that they were never treated with respect, but two respondents (0.3%) felt that their privacy needs were never met.

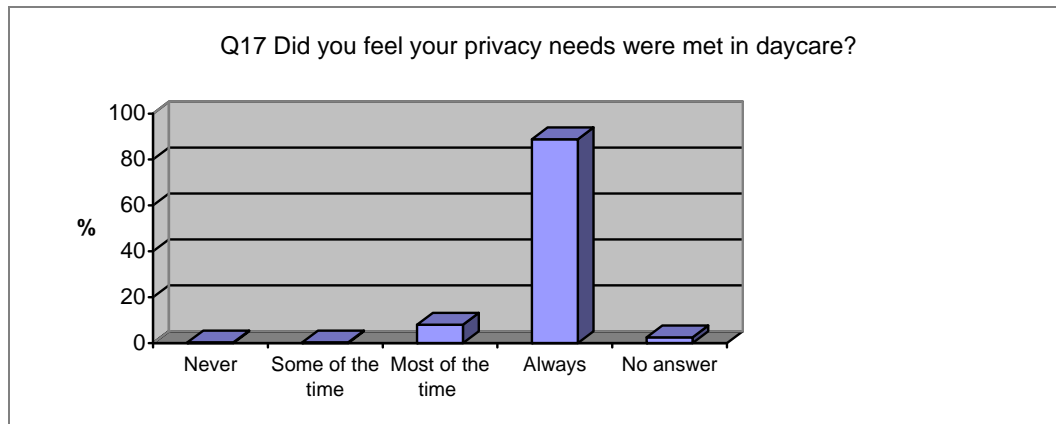
Q16 Did you feel you were treated with respect and dignity in daycare?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	0	0.0	0.0 – 0.0
Most of the time	20	3.4	0.0 – 7.5
Always	565	94.6	89.8 - 100
No answer	12	2.0	0.0 – 6.1
Total	597	100	



Q17 Did you feel your privacy needs were met in daycare?

	N	Average (%)	Range (%)
Never	2	0.3	0.0 – 2.5
Some of the time	2	0.3	0.0 – 2.1
Most of the time	48	8.0	2.0 – 15.6
Always	530	88.8	80.0 – 94.2
No answer	15	2.5	0.0 – 10.0
Total	597	100	



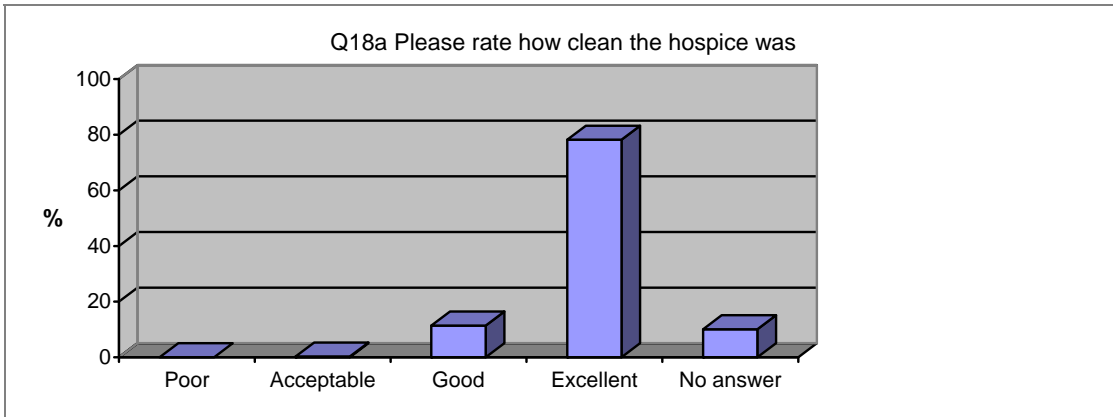
Daycare facilities and services

The type of facilities and services offered in daycare can vary greatly. This survey concentrated on general questions about facilities and services which would be applicable to all hospices. It asked about awareness of complaints procedures, what they thought about the quality of the catering, the activities available, the number of staff and volunteers available when needed, and also views on the daycare premise itself, by asking questions about the general environment/surroundings and the cleanliness of the building(s). The response options were simplified from the previously used 5-point scale (from poor to excellent) to the four options poor, acceptable, good, excellent, which should be taken into account when making comparisons over time.

Patients were asked to rate the quality of facilities and services, which were viewed by the majority to be of a high standard and rated as excellent: how clean the hospice was (78%), the activities available to take part in (52%) and the general environment and surroundings (70%). Although overall satisfaction was generally high there is a decrease in those giving an excellent rating to how clean the hospice was and to the general environment and surroundings (down by 10% and 11% on the previous survey). None rated cleanliness as poor, whereas 1% felt that the available activities of their hospice were poor. Overall patients were least impressed with the activities available. As before there was considerable variation between the different benchmark hospices, with the range of responses for rating the activities available to take part in as excellent ranging from 46%-76%, and the proportions rating the general environment as excellent ranging from 44%-88%. Respondents were invited to make further comments on the facilities and services which can be found in the 3.4 textual comments section of this report.

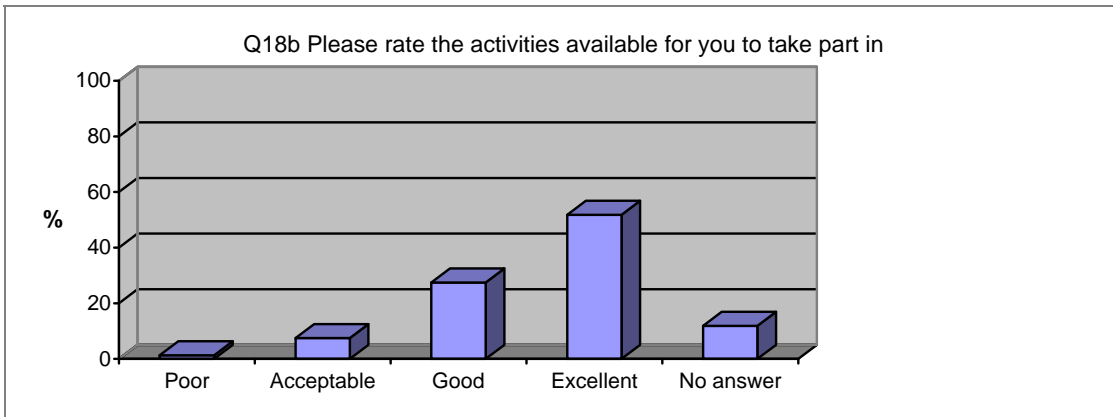
Q18a Please rate how clean the hospice was

	N	Average (%)	Range (%)
Poor	0	0.0	0.0 – 0.0
Acceptable	2	0.3	0.0 – 2.2
Good	68	11.4	4.2 – 33.3
Excellent	467	78.2	60.0 – 91.7
No answer	60	10.1	0.0 – 14.3
Total	597	100	



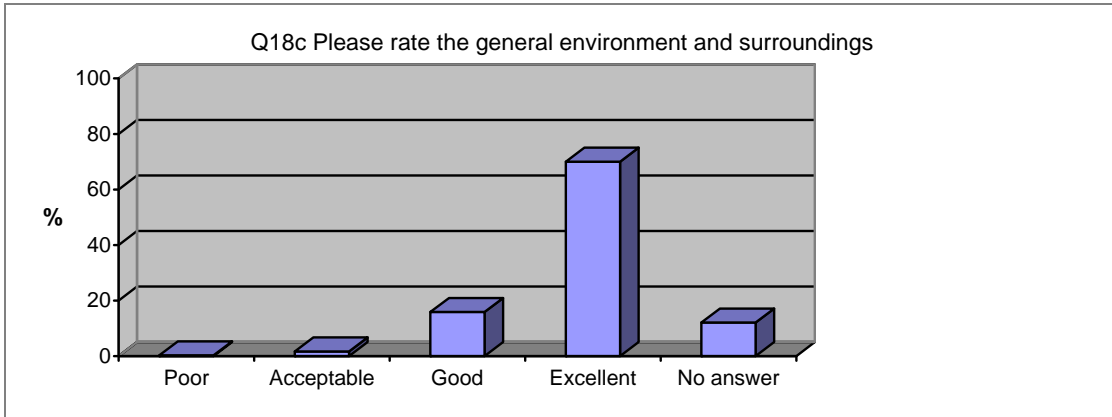
Q18b Please rate the activities available for you to take part in

	N	Average (%)	Range (%)
Poor	8	1.3	0.0 – 4.0
Acceptable	45	7.5	0.0 – 5.9
Good	164	27.5	2.0 – 21.6
Excellent	309	51.8	46.3 – 76.0
No answer	71	11.9	0.0 – 12.2
Total	597	100	



Q18c Please rate the general environment and surroundings

	N	Average (%)	Range (%)
Poor	2	0.3	0.0 – 2.5
Acceptable	10	1.7	0.0 – 8.9
Good	95	15.9	6.3 – 40.0
Excellent	418	70.0	44.4 – 87.5
No answer	72	12.1	2.3 – 12.2
Total	597	100	



The 2010/11 survey asked if patients had concerns about the about staff washing their hands and if they were bothered by noise. Over half (55%) said they never had any concerns about staff washing their hands, and 10% said they always had concerns about this. Around a third said they did not notice (22%) or did not reply (10%).

Q19 While in daycare did you have any concerns that staff were not washing their hands?

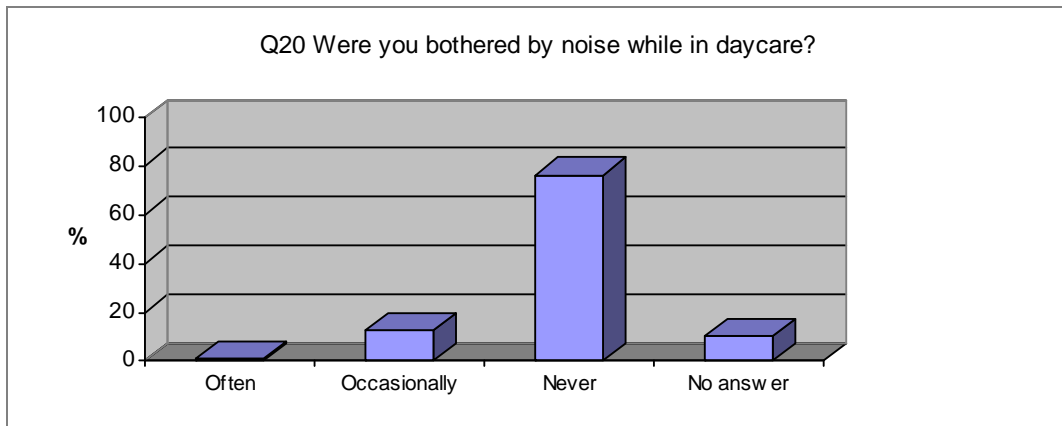
	N	Average (%)	Range (%)
Never	326	54.6	42.5 – 70.0
Some of the time	8	1.3	0.0 – 4.1
Most of the time	10	1.7	0.0 – 4.4
Always	57	9.5	4.2 – 22.5
No answer	62	10.4	1.9 – 10.2
Did not notice	134	22.4	
Total	597	100	



Very few people said they were often bothered by noise (1%), 13% said they were occasionally bothered, and over three quarters (76%) were never bothered by noise.

Q20 Were you bothered by noise while in daycare?

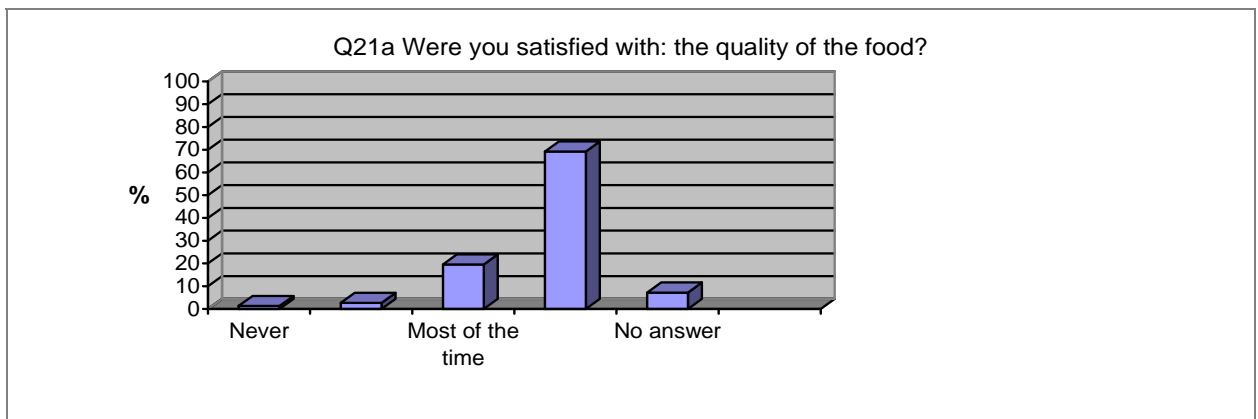
	N	Average (%)	Range (%)
Often	5	0.8	0.0 – 5.0
Occasionally	76	12.7	0.0 – 25.0
Never	455	76.2	68.9 – 94.2
No answer	61	10.2	0.0 – 8.2
Total	597	100	



Similar to the last survey 69% were always satisfied with the quality of the catering, and only 1% were never satisfied with the catering. Although the majority of daycare patients were happy with the quality of the catering, there was again great variation between the different benchmark hospices, and across the benchmark hospices the percentage that were always satisfied with the quality of the catering ranged from 54% to 88%. In the 2010/11 survey people were additionally asked about the choice of food available. Results were similar to the question about the quality of the food, with 63% saying they were always satisfied, and only 1% saying they were never satisfied with the choice of food.

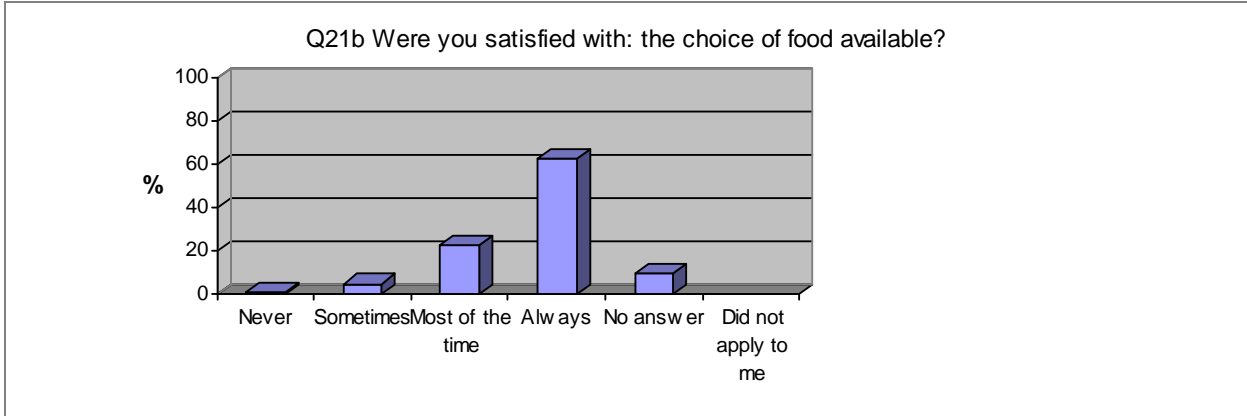
Q21a Were you satisfied with: the quality of the food?

	N	Average (%)	Range (%)
Never	8	1.3	0.0 – 4.1
Sometimes	16	2.7	0.0 – 8.3
Most of the time	117	19.6	8.2 – 41.9
Always	413	69.2	53.5 – 87.5
No answer	43	7.2	2.3 – 15.0
Total	597	100	



Q21b Were you satisfied with: the choice of food available?

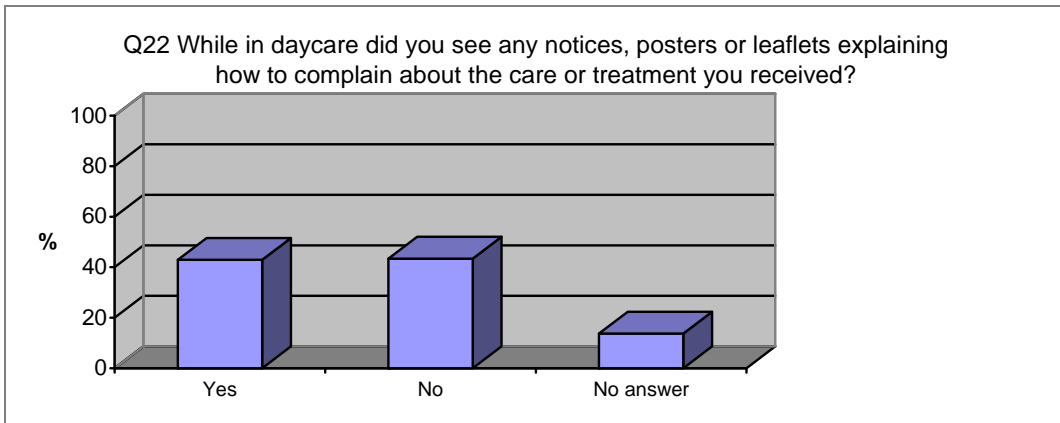
	N	Average (%)	Range (%)
Never	6	1.0	0.0 – 2.5
Sometimes	28	4.7	0.0 – 12.5
Most of the time	134	22.4	11.1 – 37.2
Always	373	62.5	45.8 – 85.0
No answer	56	9.4	0.0 – 18.4
Total	597	100	



Finally, the survey asked if daycare patients had seen notices, posters or leaflets explaining how to make a complaint. Less than half (43%) said they had seen notices, posters or leaflets, and a similar number (43%) said they had not. 14% did not answer. Results varied widely between the benchmark hospices from as low as a quarter (25%) to nearly two thirds (63%) saying they had seen notices, posters or leaflets describing how they could make a complaint. This question has been updated and had been worded differently in 2008/09 when the survey simply asked if patients were aware of how to make a complaint. At that time 66% said they were aware and 27% said they were not aware of what to do if they wanted to make a complaint. The other difference between 2010/11 and the previous survey was that in 2008/09 the benchmark hospices did not vary so widely on the percentage saying they knew how to make a complaint.

Q22 While in daycare did you see any notices, posters or leaflets explaining how to complain about the care or treatment you received?

	N	Average (%)	Range (%)
Yes	256	42.9	25.0 – 62.5
No	259	43.4	27.1 – 57.8
No answer	82	13.7	7.5 – 18.5
Total	597	100	



3.3 Average Daycare Results Overall (all 37 hospices)

The following results report the average responses of all participants aggregated together from 37 hospices who took part in the daycare survey. The total number of completed questionnaires received from daycare patients was 1150 (although for one hospice a photocopying error increased the number of missing answers since 35 people did not receive Q1d - Q5, Q10 - Q13 and Q18 - Q20).

Service: Daycare
N: 1150

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

Yes	No	Can't remember	No answer
778 (67.7%)	229 (19.9%)	106 (9.2%)	37 (3.2%)

Q1a If you looked at the leaflet or booklet, was it easy to understand?

Yes	No	Can't remember	No answer
719 (90.1%)	1 (0.1%)	34 (4.3%)	44 (5.5%)
Did not look at the leaflet or booklet: 17			
Not applicable: 335			

Q1b If you looked at the leaflet or booklet, was it helpful?

Yes	No	Can't remember	No answer
719 (90.1%)	4 (0.5%)	50 (6.3%)	25 (3.1%)
Did not look at the leaflet or booklet: 17			
Not applicable: 335			

Q1c If you looked at the leaflet or booklet, was there anything that was not correct?

Yes	No	Can't remember	No answer
21 (2.6%)	597 (74.5%)	151 (18.9%)	32 (4.0%)
Did not look at the leaflet of booklet: 14			
Not applicable: 335			

Q2 Did you feel anxious at the beginning of your first visit to daycare?

Not at all anxious	Anxious	Very anxious	No answer
343 (29.8%)	574 (49.9%)	178 (15.5%)	55 (4.8%)

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

Not at all anxious	Anxious	Very anxious	No answer
976 (84.9%)	108 (9.4%)	10 (0.9%)	56 (4.9%)

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

Less anxious	No change	More anxious
686 (63.0%)	397 (36.5%)	6 (0.6%)

Q5 Did you use transport organised by the hospice?

Yes	No	No answer
794 (69.0%)	292 (25.4%)	64 (5.6%)

Q6 If you used hospice transport, please rate the following:

	Poor	Acceptable	Good	Excellent	No answer
Whether you were picked up on time	1 (0.1%)	65 (7.3%)	239 (27.9%)	501 (58.4%)	54 (6.3%)
Comfort of journey	7 (0.8%)	58 (6.8%)	217 (25.3%)	519 (60.5%)	57 (6.6%)
Safety of journey	1 (0.1%)	21 (2.4%)	198 (23.1%)	583 (67.9%)	55 (6.4%)

Q7 While you were in daycare did the staff involved in your care introduce themselves?

Never	Some of the time	Most of the time	Always	No answer
4 (0.3%)	19 (1.7%)	140 (12.2%)	961 (83.6%)	26 (2.3%)

Q8 While you were in daycare did staff explain what they were doing?

Never	Some of the time	Most of the time	Always	No answer
5 (0.4%)	30 (2.6%)	195 (17.0%)	890 (77.4%)	30 (2.6%)

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

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	8 (0.7%)	88 (7.7%)	1032 (89.7%)	22 (1.9%)

Q10 How satisfied were you with how involved you were in planning your care?

Not at all satisfied	Not satisfied	Satisfied	Very satisfied	No answer
1 (0.1%)	12 (1.0%)	338 (33.7%)	659 (57.3%)	90 (7.8%)

Q11 Have you had the opportunity to discuss your wishes for future care up until end of life (advanced care planning)?

Yes	No	No answer
489 (42.5%)	526 (45.7%)	135 (11.7%)

Q12 Did you have the opportunity to ask questions when you wanted to?

Never	Some of the time	Most of the time	Always	No answer	Did not ask any questions
4 (0.3%)	37 (3.2%)	156 (13.6%)	820 (71.3%)	81 (7.0%)	52 (4.5%)

Q13 When you had questions to ask about you treatment and care in daycare, did you receive answers that you could understand?

Never	Some of the time	Most of the time	Always	No answer
7 (0.6%)	22 (2.0%)	154 (14.20%)	817 (75.4%)	83 (7.7%)
Did not ask any questions: 67				

Q14 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	11 (1.0%)	204 (17.7%)	906 (78.8%)	29 (2.5%)

Q15 Did you feel daycare staff made an effort to meet your religious or spiritual needs?

Never	Some of the time	Most of the time	Always	No answer
39 (3.4%)	77 (6.7%)	150 (13.0%)	706 (61.4%)	178 (15.5%)

Q16 Did you feel you were treated with respect and dignity in daycare?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	1 (0.1%)	34 (3.0%)	1085 (94.3%)	30 (2.6%)

Q17 Did you feel your privacy needs were met in daycare?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	8 (0.7%)	84 (7.3%)	1020 (88.7%)	36 (3.1%)

Q18 Please rate the following:

	Poor	Acceptable	Good	Excellent	No answer
How clean you found the hospice	0 (0.0%)	5 (0.4%)	139 (12.1%)	925 (80.4%)	81 (7.0%)
Activities available for you to take part in	14 (1.2%)	83 (7.2%)	341 (29.7%)	605 (52.6%)	107 (9.3%)
The general environment and surroundings	3 (0.3%)	24 (2.1%)	199 (17.3%)	819 (71.2%)	105 (9.1%)

Q19 While in daycare did you have any concerns that staff were not washing their hands?

Never	Some of the time	Most of the time	Always	No answer	Did not notice
629 (54.7%)	20 (1.7%)	21 (1.8%)	116 (10.1%)	81 (7.0%)	283 (24.6%)

Q20 Were you bothered by noise while in daycare?

Often	Occasionally	Never	No answer
9 (0.8%)	147 (12.8%)	914 (79.5%)	80 (7.0%)

Q21 Were you satisfied with the following:

	Never	Sometimes	Most of the time	Always	No answer
The quality of the food	12 (1.0%)	37 (3.3%)	217 (18.9%)	798 (69.4%)	86 (7.5%)
The choice of food available	13 (1.1%)	67 (5.8%)	231 (20.1%)	721 (62.7%)	118 (10.3%)

Q22 While in daycare did you see any notices, posters or leaflets explaining how to complain about the care or treatment you received?

Yes	No	No answer
501 (43.8%)	504 (43.8%)	145 (12.6%)

3.4 Daycare Textual Comments (all 37 hospices)

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

In the questionnaire there was room for respondents to write in additional remarks and clarifications. For example, to say in what way patients found information leaflets difficult to understand or unhelpful, or to elaborate on their 'ticked box' answers. In 2010/11 there were 21 questions where free text comments were invited, whereas there had only been 13 such questions in the previous survey.

Similar to the previous survey, the greatest number of written comments related to the question on confidence in the staff caring for patients (317 comments made) and the open question at the end of the questionnaire which asked for any other general comments and suggestions to help improve daycare services (359 comments). Hospice transport also received a high number of comments (281 comments made). Many patients also made comments about catering and food in their hospice (233 comments) and on what could be done to relieve anxiety on the first visit to daycare (230 commented). Two of the new questions in 2010/11 yielded significant numbers of comments; these were about having the opportunity to discuss advance care planning (181 comments) and about religious and spiritual needs being met (147 comments). Another new question established that noise levels were a problem for 64 out of the 111 daycare patients who added a comment on being bothered by noise. In total there were 2825 comments made by daycare patients.

While the responses were expected to identify areas where improvements might be made to the patients' experience, an over-whelming proportion of what patients wrote was positive and complimentary about daycare services, showing how appreciative patients were about every aspect of the care the survey asked about. Many felt there was nothing they would change about the services and care provided. A small proportion of comments (around 20%) contained suggestions that hospices could act upon, and these are the main focus in this section when summarising the comments.

Information leaflets and booklets (Q1a-d)

Some comments were made about the leaflet or booklet being difficult to understand or unhelpful. It was quite often the case that the respondents who answered used this space to say that they had not seen the hospice's information leaflet or did not have any problems with it. For example, one person said that that the booklet was not needed, and another said that all was explained in advance at a home visit.

Some people said they found the information difficult to take on board, for example it was hard to read right through, they had cognitive difficulties, or were going through a confusing and anxious time.

Comments that hospices might wish to act on came from 2% of the survey respondents. Regarding the leaflet's style, one said it was too pessimistic (unlike the hospice atmosphere), one said it put too much emphasis on how to complain, and another that the pictures should contain more younger users of hospice services. One person asked for bold type for key information (such as pain and breathlessness), one could not comment due to impaired sight and another with learning difficulties asked for leaflets with more accessible material.

Some comments were about the hospice routine and staff. For example to say how many days someone can attend, how they may be assessed and have to leave when their health improves, what long-term care is offered, and what treatments are available. One or two asked for names of medical staff or larger name tags.

Two felt that the leaflet under-played facilities that were actually offered, like the hospice ethos, the garden, the quiet room, and the range of activities, while others said the leaflet should say it was easy to get information by asking staff. Examples of features of a hospice that had pleasantly surprised patients and could have been included in the information leaflet were:

'Feeling a part of community'

'That the staff are your friends and you can talk to them about anything which you may not be able to tell family/carer.'

Some asked for changes to what was offered, such as requesting specific activities or varying the activity days. There were also quite a few requests for more information about the hospice movement and its sources of funding:

'How the hospice is dependant on voluntary subscriptions'

Relieving anxiety (Q4)

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

'I just felt anxious on my first visit (assessment) but when staff showed me the facility and the activities that patients were doing, I became more relaxed.'

'No, everything was done to relax us and the staff were brilliant.'

Some were a little unclear about the reason and purpose of daycare for them, and some said they would like to have been more prepared for what would happen:

'Could have been better informed about the order of the day.'

While others were very satisfied with their first visit:

'Day care staff arranged a pre visit to ease anxiety. I don't know what else they could have done.'

Some people felt overwhelmed by the number of people they were introduced to, while for others this was not a problem as everyone was so friendly and welcoming. Other specific sources of anxiety were raised, but usually by only one person. Examples of these were not having enough time to settle in before being examined, the hospice being very busy or under-staffed, wanting more verbal explanations, not constantly being asked if they were alright, waiting for something to happen or for transport.

Transport (Q6)

Transport elicits a lot of comments, but most of these were complimentary for the transport services provided, such as *'always reliable'*, *'professional driver, caring and trustworthy'* and *'very good'*. It was seen as a reliable service and there was much praise for the drivers in particular, who were described as friendly, helpful, considerate, caring and polite. Some also liked the way the driver escorted them from their house to the vehicle and back at the end of the day. Similarly patients gave praise for drivers who helped them to get in and out of vehicles, especially if they needed ramps or wheelchairs, and made sure they got back in-doors safely. Some said they were extremely grateful for the service otherwise they wouldn't be able to attend the hospice, and some recognised that the drivers were volunteers and were appreciative.

A few comments were critical of the drivers, such as driving too fast, not judging distance well, and asking how they are tested and trained. One person was given a new driver after voicing concerns. One person was upset by the driver talking about their family dying of cancer.

There were some comments that were less complimentary such as finding the transport uncomfortable, with the seats not being big enough, the journey being bumpy, noisy or cold, suffering travel sickness (if travelling sideways), or feeling unsafe when being moved in and out of the vehicle. There were also problems with picking up several passengers, as this made the journey longer, and some people never got to sit in the front seat. One or two preferred a car to a minibus.

There were also problems with timing, when they had trouble being ready in time, having to leave the hospice at the same time as others, the timing causing them to miss activities, not being notified of delays or cancellation, and when there were traffic delays.

Confidence in care staff and making complaints (Q9, Q22)

As before the question about **confidence in the staff** got a lot of comments with a very high proportion being complimentary. Generally patients found care staff to be friendly, helpful, and caring. Other hospice staff were also given praise including volunteers, the chaplain, the cleaner 'who smiles and says hello'. Many respondents praised the care staff and their confidence in them:

'Cannot praise the staff enough. I feel they are my lifeline. Thank you.'

'All staff are unfailingly friendly and cheerful.'

'I have confidence in all the staff. They make me feel better in myself and are very caring.'

The few critical comments were about staff being busy and having difficulty getting sufficient time with qualified staff. There were also one or two criticisms of key workers not giving help equally to all patients or not working on the days when most needed. One felt that staff were too ready to treat patients as invalids rather than being encouraged to stretch themselves.

People were invited to add further comments after the question on whether they had seen notices, posters or leaflets about **how to complain**. Many said they had no reason to complain, so had not looked for or seen notices:

'I had no need to complain - as stated before, the staff were excellent.'

Others said even if they did want to make a complaint the information was readily obtainable in material they had been given, there was a clearly visible book in the hospice, or they would find it easy to speak to a member of staff.

A surprisingly large number said their eyesight was poor, and presumably these were people who had not seen any notices. One said that notice boards were not well-positioned, another saw them but did not read them, and one felt there were just too many notices.

Involvement in care planning and communication (Q10, Q11, Q13)

Although the comments about being **involved in care planning** were not numerous, a much higher proportion suggested there is room for improvement. Some people felt that no care had been required and some went along with decisions made by others. Several felt they had not been involved, or were not aware of the process. Some said they would like more explanation, to know more about available therapies, to have regular reviews, to know what their care plan was, and to have the chance from the outset to have a discussion about what they wanted to happen. Some felt that staff (nurses) were too short of time to encourage patients to be involved in care planning.

'I do not think that I was really involved in the process of planning my care or I did not feel involved.'

'I would like to know what the care plan is.'

'It would be more helpful to know from the start why the care is being offered and to what end.'

A new question was asked about having the **opportunity to discuss end of life care** (advanced care planning) and 16% added their comments on this topic. A range of views were expressed, from it being too early or not the right time, that people did not want to address the question or preferred to take each day as it comes, to people who had had discussions or wanted to have conversations about their wishes for end of life care.

'My condition is long term, but not necessarily terminal. The question of 'end of life' has not yet arisen.'

'Although my cancer is in remission and can come back, I see no need at this point to talk about death.'

'I try not to think too much about what to expect and know that I can discuss this at any time.'

'No as am not ready to think of this as not prepared. It's enough coping with the illness.'

'Have talked about it. That's as far as I have got. My wishes have been talked about.'

'I think it is always me that brings up this topic - it is rather like "the elephant in the room".'

'The staff at the hospice were extremely compassionate in the way they handled the "end of life" information and how the final days would be adapted to suit my wishes.'

'I would have liked a bit more time spent with me in this area of care.'

Regarding **understanding answers to patients' questions** about treatment and care, quite a few patients commented that they thought the explanations were already clear enough and they could not be made clearer. Many had positive experiences as shown by this remark:

'Staff very understanding and take time to explain any problems.'

Some survey respondents said that they had hearing or communication problems or were forgetful, but that staff were willing to explain again.

One person said they would have occasionally liked help from an interpreter, and another felt that staff should check a patient has understood what was said to them. One person said that staff were not available for discussions, and two others had had trouble finding someone to talk about their care.

Support and courtesy from daycare staff (Q14, Q15, Q16, Q17)

Most people felt that there were **enough staff and volunteers** and sometimes these out-numbered the patients in daycare. There were also times when patients felt there should be more, for example, when short due to holidays or sickness, and that this could affect getting treatments like physiotherapy, bathing or manicure. There were one or two criticisms of staff or volunteers who gave less support or did not anticipate patients' needs, but these were more than compensated by positive comments, such as:

'The level of care and attention is very good.'

Many comments were made about the extent to which the hospice met daycare patients' **religious or spiritual needs**. They were fairly evenly divided between those who did not want any religious or spiritual support and those who appreciated the support from, with both factions generally saying that their wishes were respected and they were happy with the amount of support they received. Some said they felt confident that if they did have needs that they would be met. Comments included:

'Great comfort received.'

'I have no religion but staff help with my any spiritual or feeling problems.'

'I did not ask for any help with religious or spiritual needs. I am sure they would have been available if asked for.'

Some patients' comments showed that their religious and spiritual needs were not well met. For example,

'Cannot remember any specific effort.'

'Care didn't seem to conform to what might be understood as 'holistic'. There was an over emphasis on physical care.'

'I have asked for a RC Priest but nothing happens.'

No-one gave a negative comment when asked about being **treated with respect and dignity**. Daycare patients felt that staff had gone to considerable lengths to maintain their privacy and dignity and several said how different this was compared to their experiences in hospitals. Comments to illustrate this were:

'Always treated with respect.'

'I wish the outside world practised the same respect towards an individual.'

'... I actually felt like a person and was treated as such, not just a number.'

'Modesty always preserved.'

'Staff also helped to achieve a lack of embarrassment around difficult healthcare issues.'

While **privacy** needs were generally met, with survey respondents saying great care was taken with privacy and that rooms were available for private conversations to take place, some comments were made when patients were not completely satisfied. For example:

'It feels awkward to be asked how you are feeling by staff when sat next to another patient.'

'Often there was delay as there were too few rooms available to take private actions or discussions.'

Hospice cleanliness, activities, general environment and catering (Q18, Q19, Q20, Q21)

The first question in this section was about **cleanliness, activities available and the general surroundings** of the hospice. Again the majority of the remarks were positive:

'Everywhere was clean, the activities on offer were very varied and the gardens wonderful.'

'Enjoy arts and crafts done weekly as the equipment is expensive to buy.'

'I look forward to attending xxxx Hospice. It has a very pleasant, inviting caring atmosphere. The whole environment is therapeutic.'

Some comments about the surroundings referred to the impact of renovations and building work, but most comments were made about the available activities, with about 40 people (out of 1150 survey respondents) making a broad range of requests for expanding activities, for example:

'More activities for men.'

'More physical activity would have been good.'

'Possibly a more varied selection of activities would have been more acceptable and if possible changed periodically.'

'Not enough to keep me occupied.'

'More activities can be introduced to stimulate some patients and help others interact.'

'Not enough activities made it a long day.'

Not many comments were made about **staff washing their hands** (a new question) with some saying that staff always did this or that it was difficult to notice. There were hardly any concerns about hand-washing, although one person suggested disinfectant spray should be made available to patients.

Noise was commented on by more people, and most of these found noise a problem. Bothersome noise included building works, nearby aircraft which people recognised were temporary or difficult to avoid. Within the hospice the problems were with music being played too loud, noisy kitchens or dining areas, times when many people were talking at once, and these were especially a problem for people with hearing difficulties. Noise came from other patients and staff, and some patients were disturbed during quiet or relaxation sessions by other activities. Comments included:

'Background noise a little troublesome to individual conversation.'

'Only in dining room. People trying to talk above each other and serving trays banging. The room needs carpet on floor to deaden noise.'

'Extra noise interferes with hearing aids.'

'Now and then some noise was a distraction while undertaking some activity.'

Some appreciated a quiet atmosphere and for others noise was not seen as a problem, for example:

'It is good to have some noise and people talking to each other.'

'Good, quiet, relaxing atmosphere and music, plus TV provided quietly if we all agree!'

The **quality and choice of food** elicited quite a lot of comments and many of these rated the food very highly. Patients were appreciative of the menus, cooking and presentation and particularly the way individual needs were catered for:

'I have never been fed better.'

'All food was really good with plenty to choose from.'

'Food excellent served on beautifully set table and all special requests met.'

Quite a lot of comments were made about improvements to food choices and cooking, for example wanting more variety with changing and less predictable menus. Although many said their special needs were met, quite a few with dietary restrictions were critical of the lack of choice. Some specific requests were made, such as for more simple food like bacon and sausage, more fish, and more seasonal vegetables.

Overall comments (Q23)

This final opportunity to comments on the hospice overall got most response, with nearly one in three patients writing in a comment. The majority were positive about the experience of attending daycare and many reiterated points that had been made earlier.

Some said they would like to use daycare facilities for longer and one suggested an evening activity as winter approached. Requests for more activities were similar to before, such as more group activities, light exercise and more art. People also asked for more therapies such as massage, and some wanted better communication and information about their condition and treatment. Some specific comments were made about getting more comfortable seating, or improving the car-parking.

Typical responses from patients about the hospice overall are illustrated in the following comments:

'I do not think that there is any way that you can improve the care we receive.'

'... found it an excellent service, staff including all volunteers were wonderful, not at all patronising. ... all clients were treated as individuals offered choices. The atmosphere was lovely and I will be sorry to complete my allocated time and will miss attending.'

'I would like to thank everyone at the hospice where I attend all day on Tuesday; every person hospital staff, volunteers, drivers are so helpful and absolutely wonderful, nothing is too much trouble. I look forward to Tuesday every week, it is the highlight of my week.'

'Going to day care has helped my self esteem and confidence. I have had help coping with the new me, suggestions of things that might suit me etc and met others going through similar journeys.'

The Questionnaire (Q24)

Finally daycare patients were asked if they had any comments on the questionnaire. Given the amount of change and additional questions in 2010/11, it was reassuring to get a very similar response as before, with people remarking that the questionnaire clear, comprehensive and easy to complete. Even though there were more opportunities to write in comments, a few people still asked for more space to write in. Once again some found the questionnaire a bit long or had some difficulty completing it.

A few people suggested the questionnaire asked whether it had been completed by a relative or carer, and others felt that the emphasis of the questions made them more suited to inpatients. There were a small number of specific criticisms or comments for example the lack of definitions for terms like 'care' and 'treatment', and pointing out where some of the numbering or wording was confusing.

As in previous years many comments made about the questionnaire were positive, and the suggestions for change can be used in future years.

4. Results: Inpatient

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

4.1 Individual Hospice Inpatient Results

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

4.2 Benchmark Inpatient Results (4 benchmark hospices)

Four hospices reached the benchmark of a minimum of 40 or more returned inpatient questionnaires and are included in the benchmark results representing 174 patient views. This section of the report gives an overview of the aggregate results of these hospices by presenting the results in tables, charts and a written commentary of the findings for each area covered by the survey. These were provision of information about services, staff communication and care, user involvement and understanding, views of users on support and respect they receive from staff, views on hospice facilities and services. The survey questions were updated for inpatients in 2010/11 in a similar way to those for daycare patients, with inpatients also being asked about visiting arrangements and the explanations they received about taking medicines after discharge.

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

Any notable differences in the results compared to the 2008/09 survey (of +/-5% or more) are reported in the written commentary. However, as different groups of hospices reaching the benchmark in each survey make it difficult to interpret how meaningful such comparisons of similarities or differences are. This is especially the case here, as none of the four hospices in this year's benchmark results reached the inpatient benchmark in the 2008/09 survey.

Although there were considerably fewer hospices taking part in the 2010/11 inpatient survey, the number of hospices reaching the benchmark is the same as in 2008/09. These figures perhaps demonstrate that the response achievable is very much dependent on the characteristics of the hospices that decide to take part and reflective on the fact that 40 or more responses from patients at discharge can be hard to achieve for many hospice inpatient services. Therefore readers should be mindful of the fact that only four hospices are reported when interpreting these results and any differences in comparison with the last survey, as any one hospice that had much lower or higher levels of satisfaction would have a greater impact on the average result.

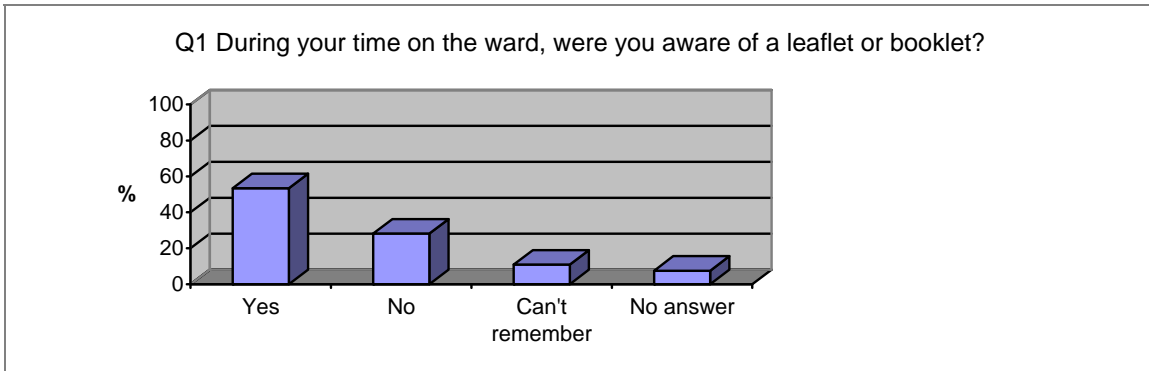
Provision of Information about Inpatient Services

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

Only 53% of inpatients in the benchmark hospices were aware of their hospice's information leaflet or booklet. In fact, no more than half were aware of the leaflet in three of the four benchmark hospices, and the percentage for all four hospices ranged from 42% to 78%. This was much lower than the 66% of inpatients being aware for **all** hospices in 2010/11, and 63% for the benchmark hospices in the previous survey.

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

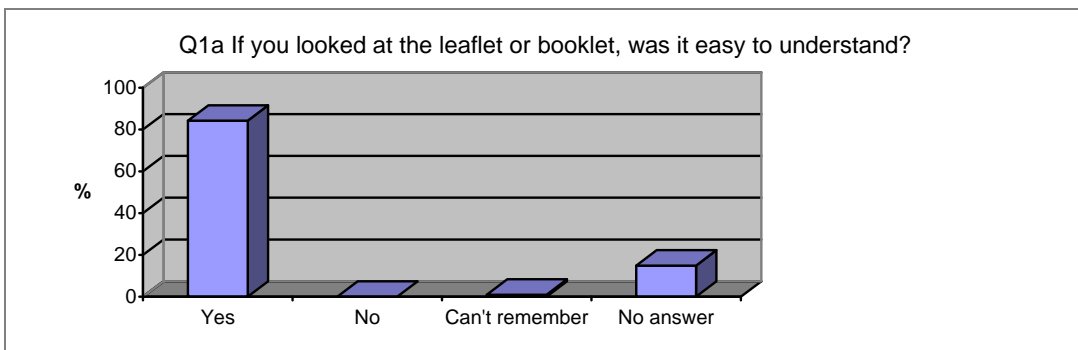
	N	Average (%)	Range (%)
Yes	93	53.4	41.5 – 78.0
No	49	28.2	14.6 – 39.0
Can't remember	19	10.9	4.9 – 19.6
No answer	13	7.5	2.4 – 10.9
Total	174	100	



Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on inpatient services, with the majority of patients (84%) who had looked at the leaflet reporting that it was easy to understand, and none (0%) saying it was not easy. 16% either said they couldn't remember or did not answer the question. The results for all hospices were better with 89% inpatients finding the information booklet easy to understand. A few inpatients commented on this - see section 4.4 for a description of the comments made.

Q1a If you looked at the leaflet or booklet, was it easy to understand?

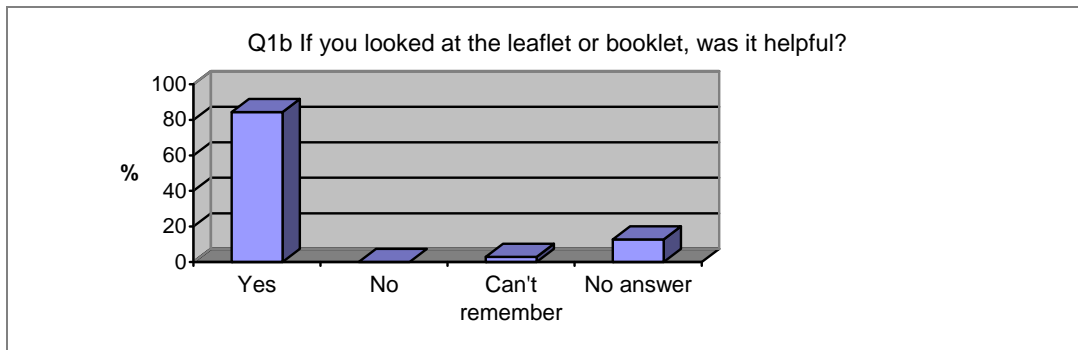
	N	Average (%)	Range (%)
Yes	85	84.2	73.9 – 90.6
No	0	0.0	0.0 – 0.0
Can't remember	1	1.0	0.0 – 5.3
No answer	15	14.9	9.4 – 26.1
Total	101	100	
Did not look at the leaflet or booklet: 5			
Not applicable: 68			



The majority of patients also felt that the leaflet included information that was helpful to them (84%) and none (0%) said it was not helpful. These figures were a small improvement on the previous survey when 81% of the benchmark inpatients found it helpful. The proportion who did not answer the question (13%) had not changed. Only 4% of patients who had looked at the leaflet said that they found something to be incorrect. A few inpatients who had looked at the leaflet made a suggestion for including further or different information (for suggestions of more information see the 4.4 textual comments section of this report).

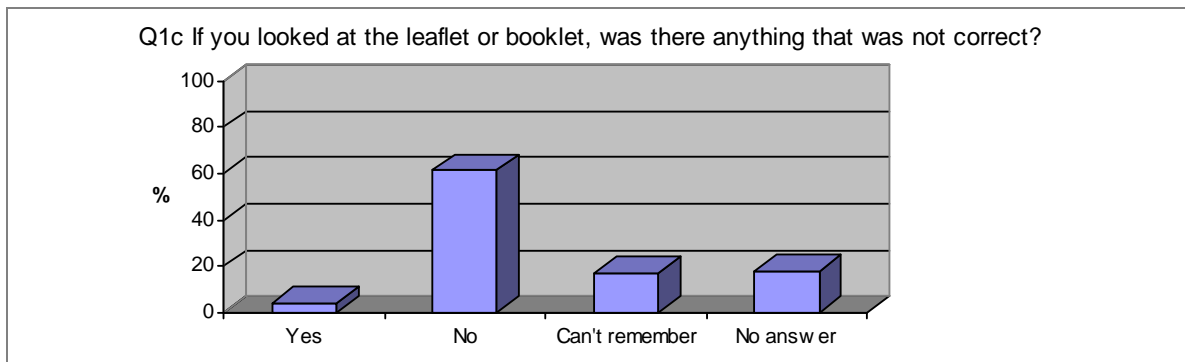
Q1b If you looked at the leaflet or booklet, was it helpful?

	N	Average (%)	Range (%)
Yes	86	84.3	77.8 – 93.9
No	0	0.0	0.0 – 0.0
Can't remember	3	2.9	0.0 – 8.7
No answer	13	12.7	6.1 – 22.2
Total	102	100	
Did not look at the leaflet or booklet: 4			
Not applicable: 68			



Q1c If you looked at the leaflet or booklet, was there anything that was not correct?

	N	Average (%)	Range (%)
Yes	4	4.0	3.0 – 5.3
No	62	61.4	40.7 – 75.8
Can't remember	17	16.8	13.6 – 22.2
No answer	18	17.8	6.1 – 33.3
Total	101	100	
Did not look at the leaflet or booklet: 5			
Not applicable: 68			

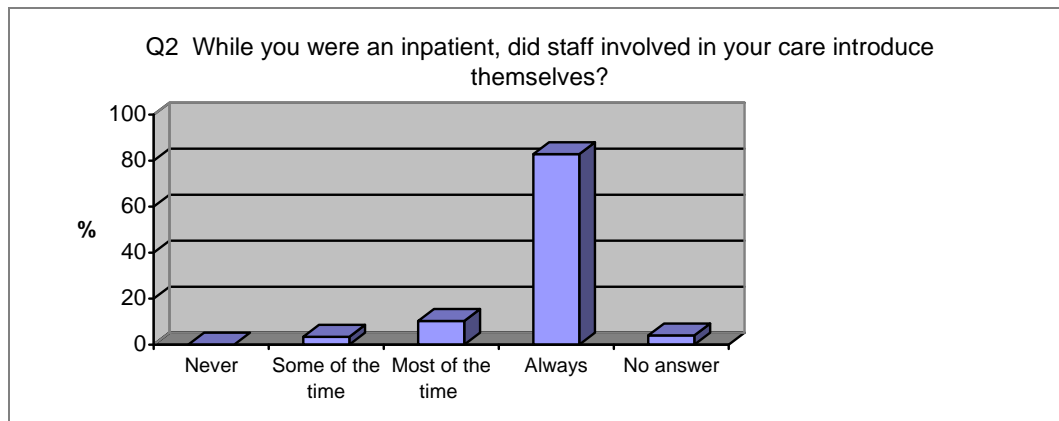


Inpatient Staff: Communication and Care

The survey asked inpatients about the communication and care they had received from staff on the ward. The majority (83%) of respondents reported that staff involved in their care always introduced themselves when they first met. A further 10% said they introduced themselves most of the time and 3% reported that staff had introduced themselves some of the time. These results were an improvement on the previous survey, both in the average and in the range of results, as the proportion of inpatients saying staff always introduced themselves varied between 72% and 88%.

Q2 While you were an inpatient, did staff involved in your care introduce themselves?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	6	3.4	2.2 – 4.9
Most of the time	18	10.3	7.3 – 17.4
Always	143	82.8	71.7 – 87.8
No answer	7	4.0	2.2 – 6.5
Total	174	100	

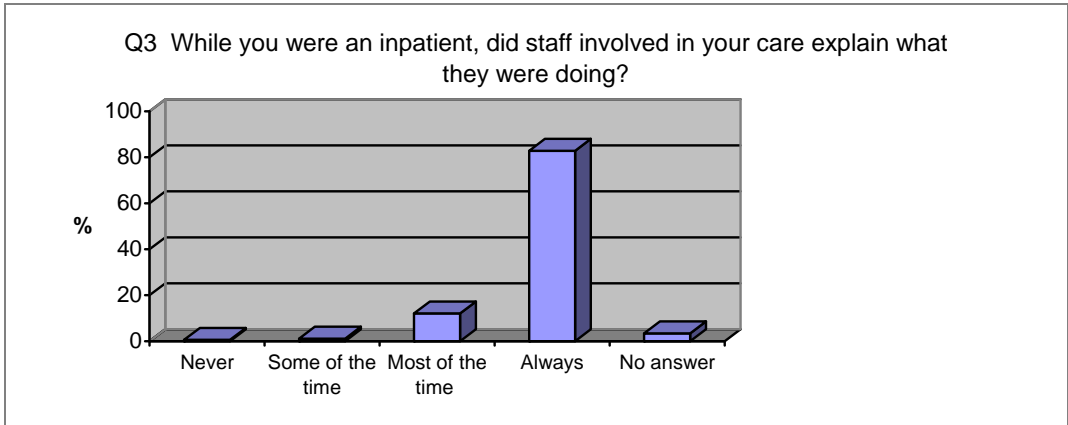


As well as staff introducing themselves, patients were asked if the staff gave explanations for what they were doing when involved in their care. Results here were very good with 83% of respondents reporting that staff always explained what they were doing, which is an increase of 16 percentage points on the previous survey. 12% reported that they explained most of the time, and only three patients reported that staff explained what they were doing less often. Performance levels were good across the benchmark hospices.

Inpatients were also asked whether they had confidence in the staff that were caring for them. The response was very positive with 88% reporting they always had confidence, and 8% said they had confidence in staff most of the time. Respondents were invited to make further comments on their confidence in staff, and many did. An overview of all comments can be found in the 4.4 textual comments section of this report.

Q3 While you were an inpatient, did staff involved in your care explain what they were doing?

	N	Average (%)	Range (%)
Never	1	0.6	0.0 – 2.4
Some of the time	2	1.1	0.0 – 2.4
Most of the time	21	12.1	4.9 – 17.4
Always	144	82.8	78.0 – 90.2
No answer	6	3.4	2.2 – 4.9
Total	174	100	



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

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	1	0.6	0.0 – 2.4
Most of the time	14	8.0	6.5 – 10.9
Always	153	87.9	84.8 – 91.3
No answer	6	3.4	2.2 – 4.9
Total	174	100	

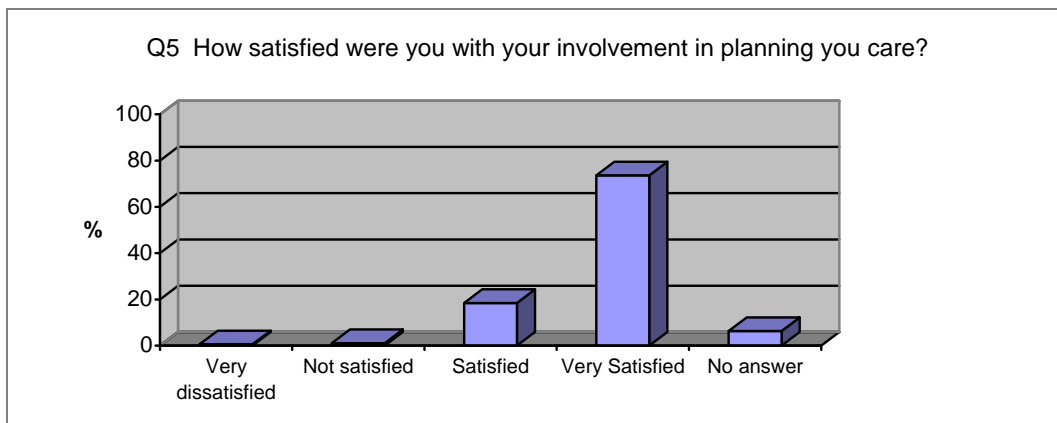


Inpatient user involvement and understanding

Patients were asked how satisfied they had been with their involvement in the planning of their care while on the ward as an inpatient. 74% of respondents were very satisfied (which is 6 percentage points higher than for all hospices and 12 points higher than the last survey). 18% were satisfied with the level of involvement in their care, only three people (<2%) were not satisfied, and 6% didn't answer the question. These respondents were given the opportunity to suggest how they could be involved more in the planning of their care (for these suggestions of more information see the 4.4 textual comments section of this report).

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

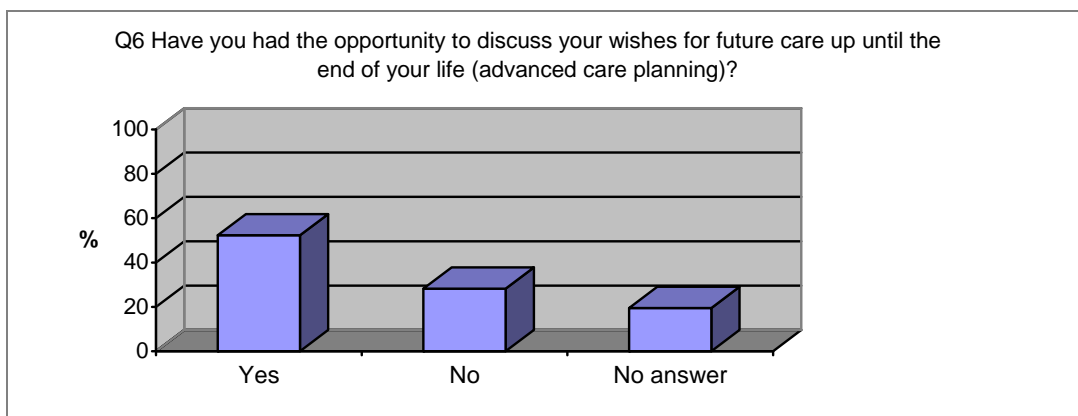
	N	Average (%)	Range (%)
Not at all satisfied	1	0.6	0.0 -2.2
Not satisfied	2	1.1	0.0 – 2.2
Satisfied	32	18.4	10.9 – 26.8
Very Satisfied	128	73.6	68.3– 80.4
No answer	11	6.3	4.9 – 7.3
Total	174	100	



A new question was included about having the opportunity to discuss wishes for future care up until end of life, or advanced care planning. Just over a half (52%) felt they had had this opportunity, 28% felt they had not, and 20% gave no answer. The response between hospices did not differ greatly, ranging from 46%-63% inpatients saying they had the opportunity to discuss their care at the end of life. Comments on this topic were invited and are summarised in section 4.4.

Q6 Have you had the opportunity to discuss your wishes for future care up until the end of your life (advanced care planning)?

	N	Average (%)	Range (%)
Yes	91	52.3	45.7 – 63.4
No	49	28.2	21.7 – 34.1
No answer	34	19.5	9.8 – 32.6
Total	174	100	

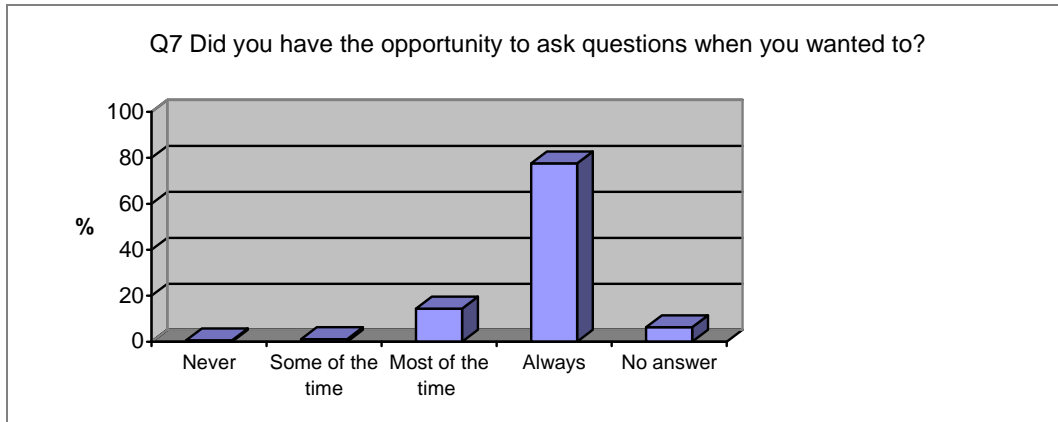


Inpatients were asked if they had had the opportunity to ask questions when they wanted to. 78% said they always had the opportunity and 14% said most of the time. Only three (<2%) had less or no opportunity to ask questions and 6% gave no answer.

The survey also asked if people understood the explanations given to them about their care whilst on the ward. Just over half of respondents (73%) felt that they always understood the explanations given to them (this is a large increase of 20 percentage points compared to the last survey). 14% said they understood most of the time, 2% said they sometimes understood explanations given to them, and no-one said they never understood. Some respondents suggested ways of making their hospice's explanations clearer (for suggestions see the 4.4 textual comments sections in this report).

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

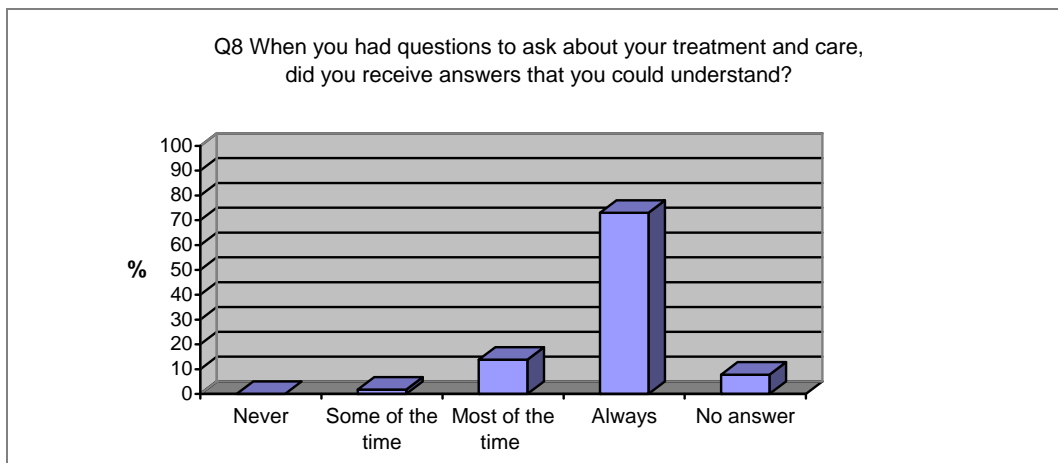
	N	Average (%)	Range (%)
Never	1	0.6	0.0 – 2.2
Some of the time	2	1.1	0.0 – 2.4
Most of the time	25	14.4	10.9 – 17.1
Always	135	77.6	71.7 – 82.6
No answer	11	6.3	4.9 – 8.7
Total	174	100	



Q8 When you had questions to ask about your treatment and care, did you receive answers that you could understand?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	3	1.8	0.0 – 6.8
Most of the time	24	13.8	6.8 – 18.6
Always	127	73.0	69.8 – 81.8
No answer	13	7.8	4.5 – 11.6
Total	167	100	

Did not ask any questions: 7

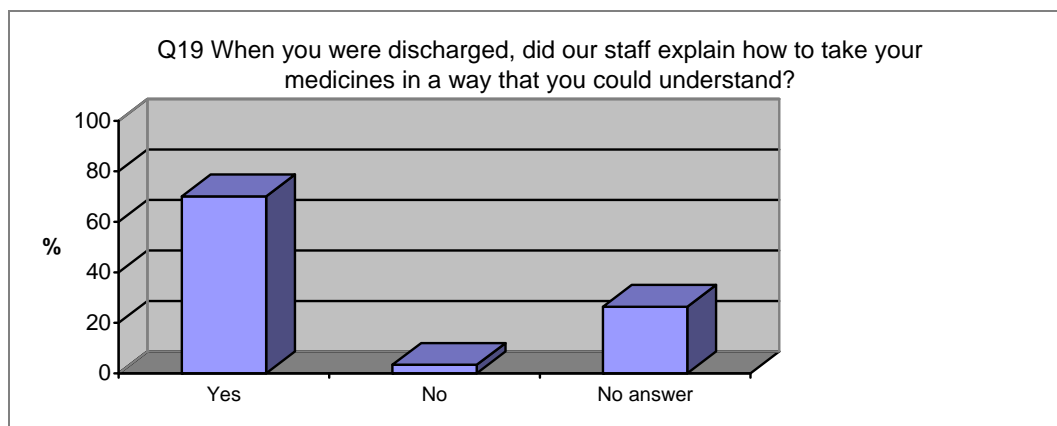


Finally there was a new question about clarity of the explanations inpatients were given on discharge about how to take medication. In one hospice over half failed to answer this question, affecting average figures for the benchmark hospices. In this hospice it seems that quite a few service users received the survey before they were discharged making this question impossible to answer. Excluding this hospice from the range data, the

survey showed that between 74%-93% said they could understand the explanation, 0%-9% said they could not, and between 7%-17% gave no answer.

Q19 When you were discharged, did our staff explain how to take your medicines in a way that you could understand?

	N	Average (% for all 4 benchmark hospices)	Range (% excluding 1 hospice with 61% no answer)
Yes	122	70.1	73.9 – 92.7
No	6	3.4	0.0 – 8.7
No answer	46	26.4	7.3 – 17.4
Total	174	100	



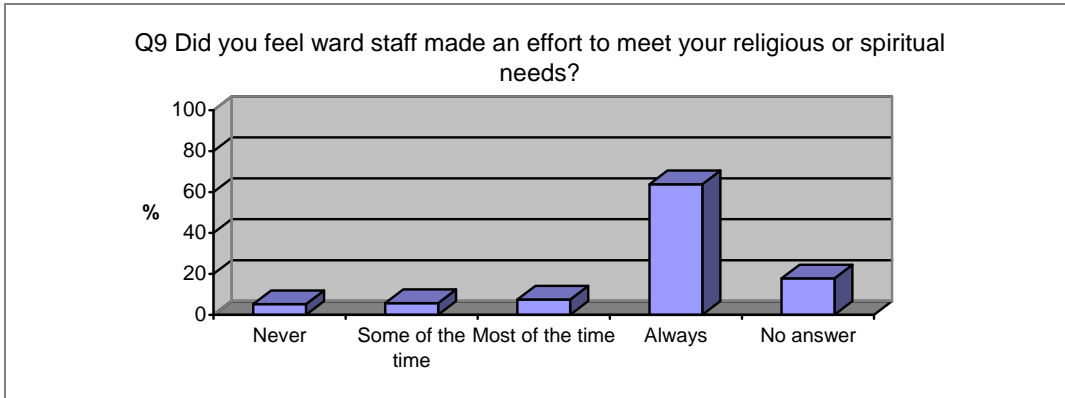
Views of Inpatients on the Support and Courtesy of Staff

A number of questions were asked in the survey about inpatient views on the support and courtesy of the staff looking after them on the ward. Generally respondents were positive about the support they received from staff. Results in this section have not changed from those found in the previous survey.

A new question was asked about whether daycare staff made an effort to meet religious or spiritual needs. Nearly two-thirds (64%) felt that staff did this all the time and a further 8% said staff made an effort most of the time. 11% of people felt that staff tried to meet religious or spiritual needs less often or never, and 18% did not answer. The proportion not replying was quite high, but seems to be explained from the comments shown in section 4.4 where some inpatients said they did not have religious or spiritual needs.

Q9 Did you feel ward staff made an effort to meet your religious or spiritual needs?

	N	Average (%)	Range (%)
Never	9	5.2	0.0 – 8.7
Some of the time	10	5.7	2.4 – 8.7
Most of the time	13	7.5	2.4 – 10.9
Always	111	63.8	45.7 – 76.1
No answer	31	17.8	10.9 – 26.1
Total	174	100	



The vast majority of inpatients generally felt that staff treated them with respect and dignity. 90% felt they were always treated in this manner, and 3% said most of the time. None felt they were never treated with respect and dignity. 6% did not answer this question.

The proportion of respondents feeling that their privacy needs were always met has increased 8 percentage points to 86%. 8% felt their privacy needs were met most of the time and two respondents felt their privacy needs were only met some of the time.

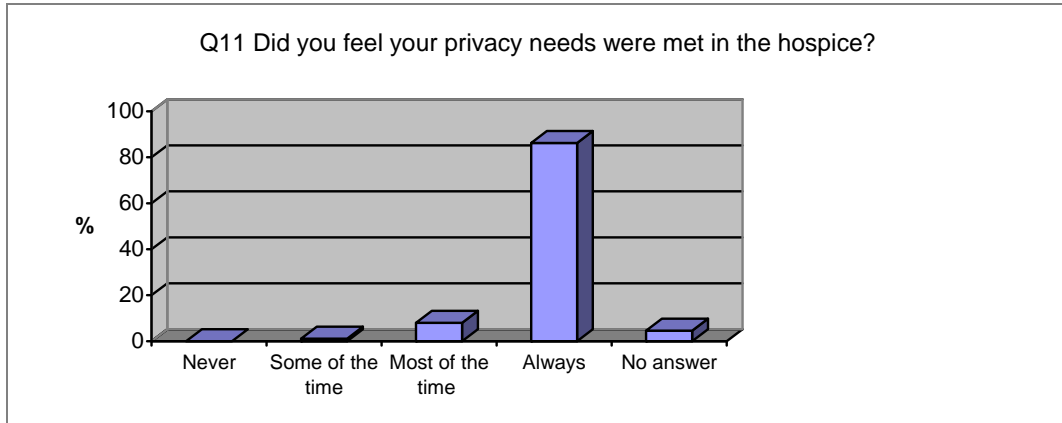
Q10 Were you treated with respect and dignity in the hospice?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	1	0.6	0.0 – 2.2
Most of the time	6	3.4	0.0 – 9.8
Always	157	90.2	87.0 – 93.5
No answer	10	5.7	2.4 – 8.7
Total	174	100	



Q11 Did you feel your privacy needs were met in the hospice?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	2	1.1	0.0 – 4.3
Most of the time	14	8.0	4.3 – 10.9
Always	150	86.2	84.8 – 87.8
No answer	8	4.6	2.4 – 7.3
Total	174	100	



Inpatient Facilities and Services

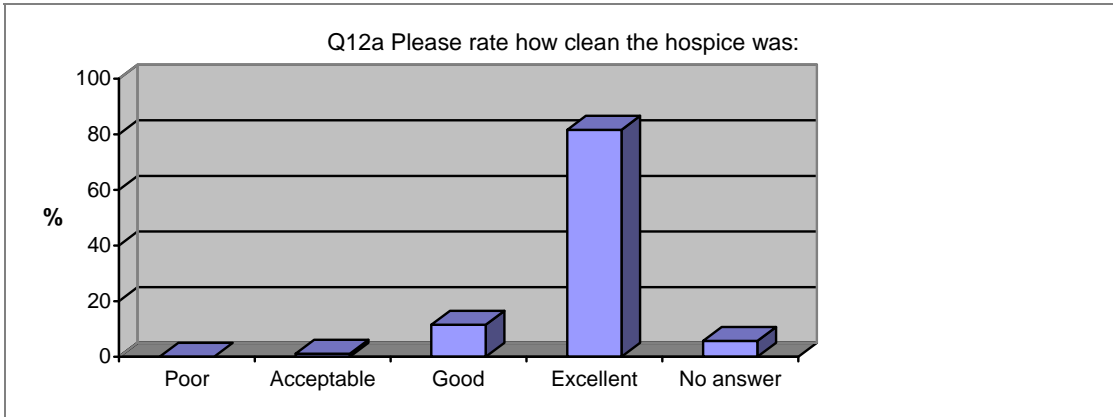
The survey asked a range of questions about how patients rate the facilities and services available to inpatients in their hospice. It asked for views on the general environment, including the cleanliness of the premises, noise and staff hand-washing. Also about the available activities, the quality of the catering, their satisfaction with visiting arrangement, how to call for help, and how to make a complaint.

When asked to rate the facilities and services the following were viewed by the majority to be of a high standard and rated as excellent: the cleanliness of the premises (82%) and the general environment and surroundings (79%). Very few (1%) rated these as poor or acceptable. In contrast, a minority rated the available activities as excellent (26%), 24% rated them as good, and they were rated as acceptable or poor by 6% and 3% respectively. Quite a large proportion (40%) gave no reply to the question about available activities, some saying it did not apply to them. Due to the 2008/9 survey using a poor to excellent 5-point rating scale, the latest findings cannot easily be compared to previous ones.

Ratings for cleanliness and the general environment were high, and there has been improvement among the benchmark hospices in the range rating cleanliness as excellent. On the other hand, the level of dissatisfaction with activities was quite high and hospices may wish to investigate this further. Respondents were invited to make further comments on these facilities and services which can be found in the 4.4 textual comments sections of this report. These clarified why some inpatients did not take part in activities, for example when they were not fit enough.

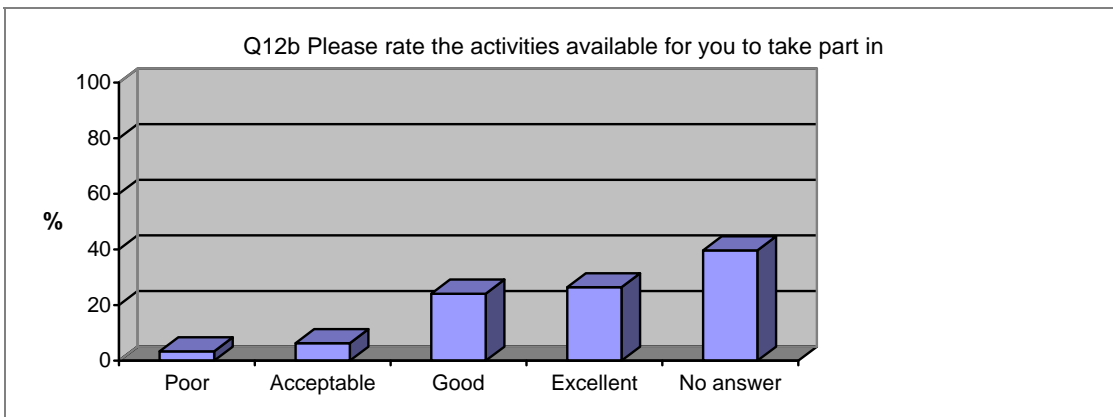
Q12a Please rate how clean the hospice was:

	N	Average (%)	Range (%)
Poor	0	0.0	0.0 – 0.0
Acceptable	2	1.1	0.0 – 2.4
Good	20	11.5	6.5 – 17.1
Excellent	142	81.6	70.7 – 87.8
No answer	10	5.7	4.3 – 9.8
Total	174	100	



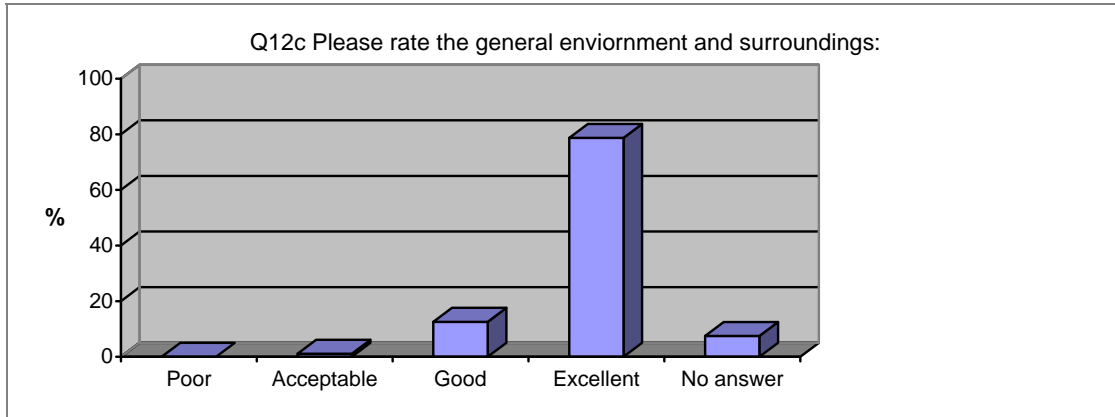
Q12b Please rate the activities available for you to take part in

	N	Average (%)	Range (%)
Poor	6	3.4	0.0 – 4.9
Acceptable	11	6.3	4.9 – 7.3
Good	42	24.1	19.6 – 31.7
Excellent	46	26.4	19.5 – 34.8
No answer	69	39.7	34.8 – 43.9
Total	174	100	



Q12c Please rate the general environment and surroundings:

	N	Average (%)	Range (%)
Poor	0	0.0	0.0 – 0.0
Acceptable	2	1.1	0.0 – 2.2
Good	22	12.6	7.3 – 15.2
Excellent	137	78.7	71.7 – 87.8
No answer	13	7.5	4.9 – 10.9
Total	174	100	

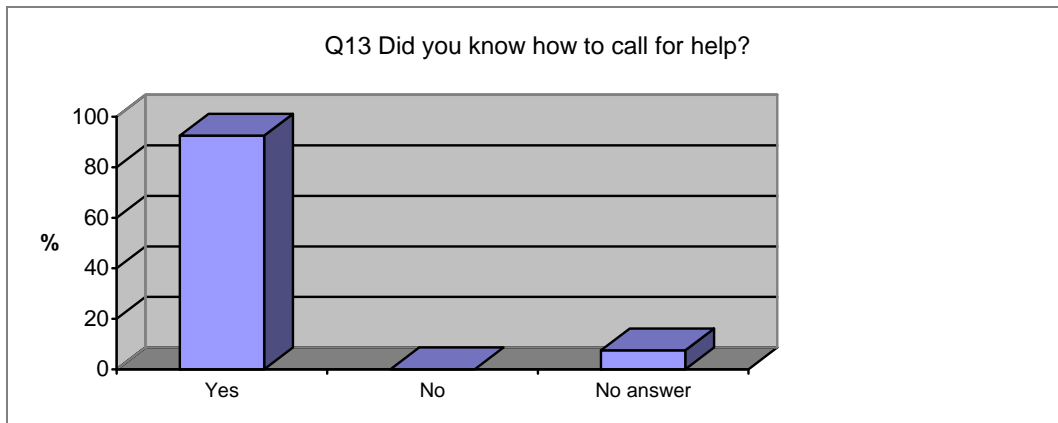


Almost all inpatients in the survey (93%) knew how to call for help while they were in hospice care (10 percentage points more than the previous survey). None said they did not know, and 8% gave no answer.

Of those who needed to call for assistance while they were an inpatient, the great majority (82%) were always satisfied with the response they got, 9% were satisfied most of the time with the response, and none were less satisfied. 9% gave no answer. Compared to the previous survey there has been improvement in the range of performance with a much higher minimum level (74% always satisfied compared to a minimum of 40% in 2008/9).

Q13 Did you know how to call for help?

	N	Average (%)	Range (%)
Yes	161	92.5	87.8 – 97.8
No	0	0.0	0.0 – 0.0
No answer	13	7.5	2.2 – 12.2
Total	174	100	

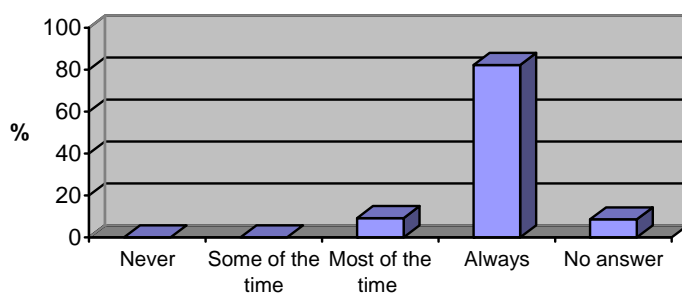


Q14 If you needed to call for help, were you satisfied with the response?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	0	0.0	0.0 – 0.0
Most of the time	15	9.2	4.7 – 21.1
Always	134	82.2	73.7 – 86.0
No answer	14	8.6	5.3 – 12.8
Total	163	100	

Not applicable as did not need to call for help: 11

Q14 if you needed to call for help, were you satisfied with the response?

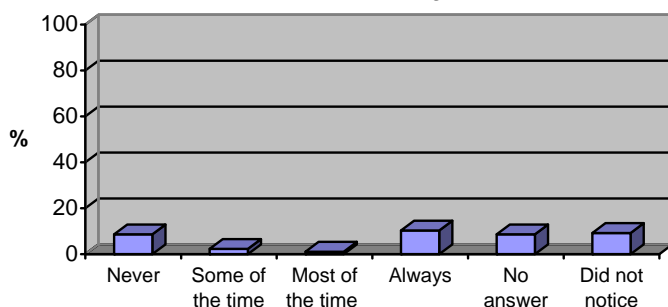


The 2010/11 survey asked if patients had concerns about the about staff washing their hands and if they were bothered by noise. Over two thirds (68%) said they never had any concerns about staff washing their hands, and 10% said they always had concerns about this. Some said they did not notice (9%) or did not reply (9%).

Q15 While on the ward did you have any concerns that staff were not washing their hands?

	N	Average (%)	Range (%)
Never	119	68.4	61.0 – 75.6
Some of the time	4	2.3	0.0 – 4.9
Most of the time	2	1.1	0.0 – 2.4
Always	18	10.3	2.4 – 21.7
No answer	15	8.6	4.9 – 14.6
Did not notice	16	9.2	2.2 – 15.2
Total	174	100	

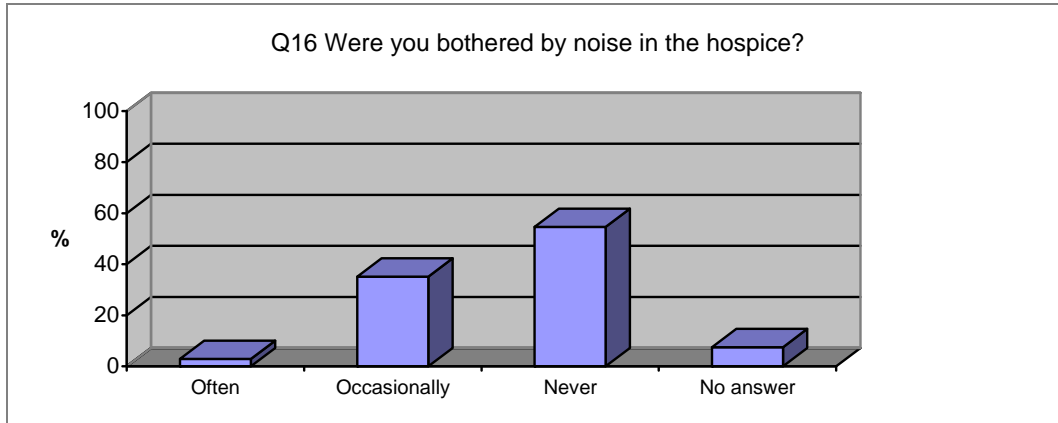
Q15 While on the ward did you have any concerns that staff were not washing their hands?



A few people said they were often bothered by noise (3%), 35% said they were occasionally bothered, and over a half (55%) were never bothered by noise. Noise appeared to be more of a problem for inpatients compared to daycare patients, and many added a comment about noise, these are summarised in section 4.4 on textual comments.

Q16 Were you bothered by noise in the hospice?

	N	Average (%)	Range (%)
Often	5	2.9	0.0 – 9.8
Occasionally	61	35.1	31.7 – 37.0
Never	95	54.6	46.3 – 63.0
No answer	13	7.5	2.2 – 14.6
Total	174	100	

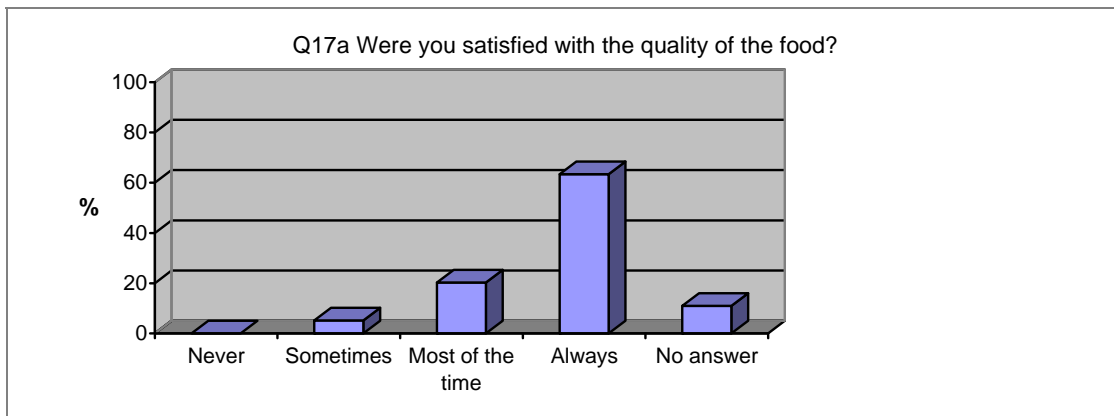


63% were always satisfied with the quality of the food, which was 6 percentage points down on the previous survey. 20% were satisfied most of the time, and 5% were only satisfied with the food some of the time. Although the majority of daycare patients were happy with the quality of the catering, there was variation between the different benchmark hospices, and across the benchmark hospices the percentage that were always satisfied with the quality of the catering ranged from 55% to 73%. In the 2010/11 survey people were additionally asked about the choice of food available. Results were similar to the question about the quality of the food, with 66% saying they were always satisfied, and 6% saying they were only sometimes satisfied with the choice of food.

Q17a Were you satisfied with the quality of the food?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Sometimes	9	5.2	2.2 – 7.5
Most of the time	35	20.3	13.3 – 27.5
Always	109	63.4	55.0 – 73.3
No answer	19	11.0	8.9 – 14.6
Total	172	100	

Did not apply: 2



Q17b Were you satisfied with the choice of food available?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Sometimes	10	5.8	2.2 – 12.5
Most of the time	30	17.4	13.0 – 24.4
Always	113	65.7	53.7 – 75.6
No answer	19	11.0	8.9 – 14.6
Total	172	100	
Did not apply: 2			

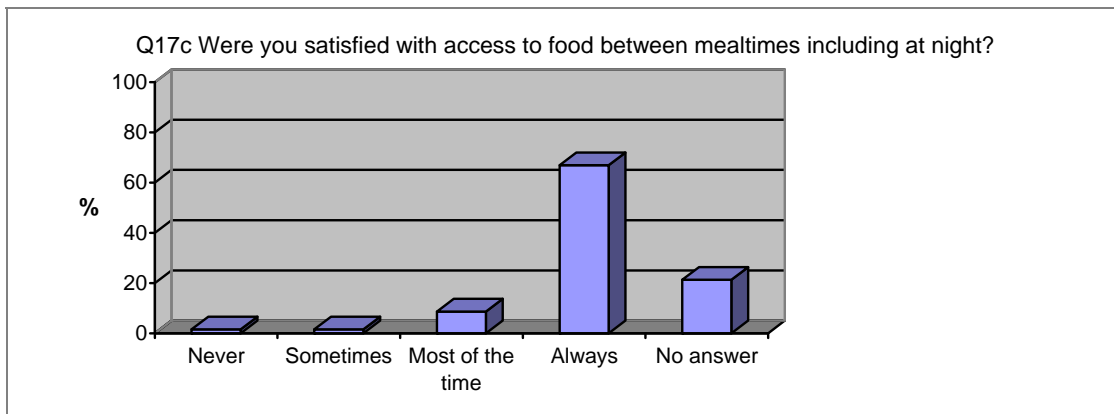


The survey asked what inpatients thought about access to food other than at meal times including at night. Again results were quite similar to the previous questions on catering, with 67% always satisfied with access to food other than at meal times.

On catering questions, there was less variation between the benchmark hospices in 2010/11 compared to the previous survey. Although there is room for improvement in these areas, it is recognised that catering for everyone, as can be seen from the further comments which can be found in section 4.4 of this report.

Q17c Were you satisfied with access to food between mealtimes including the night?

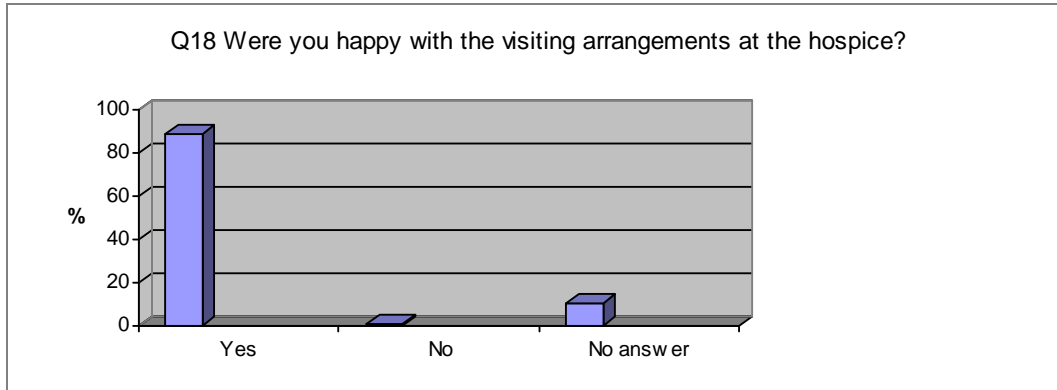
	N	Average (%)	Range (%)
Never	2	1.6	0.0 – 3.0
Sometimes	2	1.6	0.0 – 3.0
Most of the time	11	8.7	5.4 – 15.2
Always	85	66.9	60.6 – 72.4
No answer	27	21.3	18.2 – 25.0
Total	127	100	
Did not apply: 47			



A new question in 2010/11 was about satisfaction with visiting arrangements. All hospices scored highly on this, and for benchmark hospices 90% said they were happy with visiting arrangements and hardly anyone said they were not.

Q18 Were you happy with the visiting arrangements at the hospice?

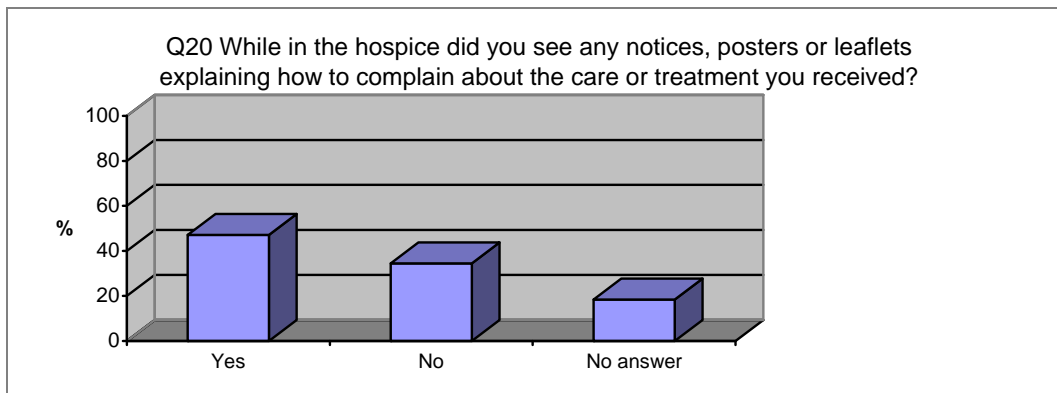
	N	Average (%)	Range (%)
Yes	155	89.1	85.4 – 91.3
No	1	0.6	0.0 – 2.2
No answer	18	10.3	8.7 – 14.6
Total	174	100	



Finally, the survey asked if inpatients had seen notices, posters or leaflets explaining how to make a complaint. Less than half (47%) said they had seen notices, posters or leaflets, and a similar number (35%) said they had not. 18% did not answer. Results varied between the benchmark hospices from 22% to 44% saying they had seen notices, posters or leaflets describing how they could make a complaint. This question has been updated and worded differently compared to 2008/09 when the survey simply asked if patients were aware of how to make a complaint. At that time 62% said they knew compared to 29% who said they did not know what to do if they wanted to make a complaint. The textual replies in section 4.4 showed that some inpatients said they did not have the opportunity to see posters as they had not left their rooms during their inpatient stay.

Q20 While in the hospice did you see any notices, posters or leaflets explaining how to complain about the care or treatment you received?

	N	Average (%)	Range (%)
Yes	82	47.1	39.1 – 63.4
No	60	34.5	21.7 – 43.9
No answer	32	18.4	7.3 – 34.8
Total	174	100	



4.3 Average Inpatients Results Overall (all 35 hospices)

The following results report the average responses of all participants aggregated together from all 35 hospices who took part in the inpatient questionnaire at discharge. The total number of completed questionnaires received from inpatients was 834 and all are included in the following results.

Three hospices made errors in putting the survey questionnaires together (with pages missing pages or using questions from the previous survey), and this inflated the percentage of missing answers.

Service: Inpatient N: 834

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

Yes:	No	Can't remember	No answer
546 (65.6%)	192 (23.0%)	70 (8.4%)	26 (3.1%)

Q1a If you looked at the leaflet or booklet, was it easy to understand?

Yes	No	Can't remember	No answer
481 (88.9%)	5 (0.9%)	16 (3.0%)	39 (7.2%)
Did not look at the leaflet or booklet: 31			
Not applicable: 262			

Q1b If you looked at the leaflet or booklet, was it helpful?

Yes	No	Can't remember	No answer
473 (87.4%)	4 (0.7%)	29 (5.4%)	35 (6.5%)
Did not look at the leaflet or booklet: 31			
Not applicable: 262			

Q1c If you looked at the leaflet or booklet, was there anything that was not correct?

Yes	No	Can't remember	No answer
14 (2.6%)	393 (72.8%)	93 (17.2%)	40 (7.4%)
Did not look at the leaflet or booklet: 32			
Not applicable: 262			

Q2 While you were an inpatient did the staff involved in your care introduce themselves?

Never	Some of the time	Most of the time	Always	No answer
3 (0.4%)	28 (3.4%)	125 (15.0%)	645 (77.3%)	33 (4.0%)

Q3 While you were an inpatient did the staff involved in your care explain what they were doing?

Never	Some of the time	Most of the time	Always	No answer
3 (0.4%)	20 (2.4%)	134 (16.1%)	649 (77.8%)	28 (3.4%)

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

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	13 (1.6%)	87 (10.4%)	705 (84.5%)	27 (3.2%)

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

Not at all satisfied	Not satisfied	Satisfied	Very satisfied	No answer
1 (0.1%)	13 (1.6%)	209 (25.1%)	567 (68.0%)	44 (5.3%)

Q6 Have you had the opportunity to discuss your wishes for future care up until end of life (advanced care planning)?

Yes	No	No answer
462 (55.4%)	280 (33.6%)	92 (11.0%)

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
3 (0.4%)	28 (3.4%)	163 (19.5%)	614 (73.6%)	26 (3.1%)

Q8 When you had questions to ask about you treatment and care, did you receive answers that you could understand?

Never	Some of the time	Most of the time	Always	No answer
5 (0.6%)	19 (2.4%)	155 (19.6%)	580 (73.3%)	32 (4.0%)
Did not ask any questions: 43				

Q9 Did you feel ward staff made an effort to meet your religious or spiritual needs?

Never	Some of the time	Most of the time	Always	No answer
46 (5.5%)	40 (4.8%)	77 (9.2%)	521 (62.5%)	150 (18.0%)

Q10 Did you feel you were treated with respect and dignity in the hospice?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	6 (0.7%)	37 (4.4%)	754 (90.4%)	37 (4.4%)

Q11 Did you feel your privacy needs were met in the hospice?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	14 (1.7%)	74 (8.9%)	711 (85.3%)	35 (4.2%)

Q12 Please rate the following:

	Poor	Acceptable	Good	Excellent	No answer
How clean you found the hospice	0 (0.0%)	11 (1.3%)	106 (12.7%)	677 (81.2%)	40 (4.8%)
Activities available for you to take part in	35 (4.2%)	61 (7.3%)	180 (21.6%)	274 (32.9%)	284 (34.1%)
The general environment and surroundings	2 (0.2%)	18 (2.2%)	100 (12.0%)	657 (78.8%)	57 (6.8%)

Q13 Did you know how to call for help?

Yes	No	No answer
773 (92.7%)	13 (1.6%)	48 (5.8%)

Q14 If you needed to call for help, were you satisfied with the response?

Never	Some of the time	Most of the time	Always	No answer
2 (0.3%)	13 (1.7%)	116 (15.0%)	590 (76.1%)	54 (7.0%)

Q15 While on the ward did you have any concerns that staff were not washing their hands?

Never	Some of the time	Most of the time	Always	No answer	Did not notice
545 (65.3%)	21 (2.5%)	18 (2.2%)	82 (9.8%)	60 (7.2%)	108 (12.9%)

Q16 Were you bothered by noise while in the hospice?

Often	Occasionally	Never	No answer
33 (4.0%)	294 (35.3%)	451 (54.1%)	56 (6.7%)

Q17 Were you satisfied with the following:

	Never	Sometimes	Most of the time	Always	No answer
The quality of the food	5 (0.6%)	37 (4.6%)	163 (20.1%)	529 (65.1%)	78 (9.6%)
The choice of food available	8 (1.0%)	47 (5.8%)	140 (17.2%)	534 (65.7%)	84 (10.3%)
Access to food between mealtimes, including during the night	12 (1.9%)	26 (4.2%)	58 (9.4%)	411 (66.5%)	111 (18.0)

Q18 Were you happy with the visiting arrangements at the hospice?

Yes	No	No answer
742 (89.0%)	9 (1.1%)	83 (10.0%)

Q19 When you were discharged, did our staff explain how to take your medicines in a way that you could understand?

Yes	No	No answer
653 (78.3%)	28 (3.4%)	153 (18.3%)

Q20 While in the hospice did you see any notices, posters or leaflets explaining how to complain about the care or treatment you received?

Yes	No	No answer
375 (45.0%)	320 (38.4%)	139 (16.7%)

4.4 Inpatient Textual Comments (all 35 hospices)

This section summarises inpatients' comments across all the hospices involved in the inpatient survey. Each participating hospice has also been given an individual report showing the comments made in the survey by their own patients.

The questionnaire had space for patients to write in and elaborate on their answers to some of the 'tick box' questions and respondents were also asked to make some general comments at the end of the questionnaire if they wished to. In 2010/11 there were twice as many questions where free text comments were invited, for example the questions on whether inpatients' privacy, dignity and religious/spiritual needs were met. Comments were received from respondents about information, the care staff, explanations about care and involvement in planning, catering, facilities, and the general environment of the hospice. Comments relating to confidence in the staff (232 comments), noise levels (194) and general comments on suggestions to develop the service (266) were the most numerous. There were also quite a lot (around 120-150) of comments by inpatients on the following: food, hospice activities and environment, advanced care planning and religious/spiritual needs.

The majority of comments were highly favourable and a selection of these are referred to in the summary of comments that follows. However, as the aim was to identify areas where improvements might be made to the patients' experience, this summary focuses mainly on comments that identify issues for hospices to act upon. It should be noted that the majority of suggestions for change were made by one or two people only. Overall there were 1945 comments and, a little higher than the previous survey, over a quarter (29%) identified issues for hospices to address.

Information leaflets and booklets (Q1a-d)

Respondents were asked to comment on anything they could not understand or found unhelpful or incorrect in their hospice's leaflet or booklet, and were invited to make any suggestions they had to improve it. Not many comments were made, indicating that hospices were generally effective in the way they were providing information. Some inpatients said they had not seen a leaflet or booklet or were unaware of it. One or two said they were not in the hospice long enough or were feeling too unwell to read it.

Other comments regarding the information leaflet or booklets said that certain details they felt were important had been omitted, such as about the services and help that the hospice offered to patients and their families. Some wanted to know more about the daily routines, dates and times of activities and meals, and how relatives could contact an inpatient. Others suggested information booklets should say more to describe the patient experience and the support the hospice provided.

Comments were largely positive saying the information was clear, informative and covered everything inpatients needed, for example:

'No more information required. All very informative'

'This is good information to pass onto friends'

Confidence in care staff and making complaints (Q4, Q20)

The comments about **confidence in staff** were overwhelmingly positive, with repeated views that care was excellent and could not have been better. The following are examples of what inpatients said:

'From the doctors, nurse to housekeepers and volunteers all people communicative and open'

'The nursing staff were exceptionally sensitive, perceptive and thorough in their care'

'The kindness and respect for patients was impressive. They treated each one as an individual'

'I am amazed at the standard of care I received was so consistently high'

'All staff very helpful above their call of duty'

A small proportion of the comments described problems or issues that hospices will want to note. Several commented about not knowing who were the nurses and doctors, through poor introductions or staff name badges. There were occasions when staff action was criticised, such as making a silly mistake or a having bullying attitude, and lacking confidence. One commented that bank staff were not always as sympathetic as regular staff. There were also comments about specific actions, such as not dealing with a medical problem quickly enough or effectively, not giving medication at the set times. One asked for better communication when there were delays.

When asked if they had seen notices about **how to make a complaint**, most comments were that the information was not needed as there was no reason to complain. It was also quite common for inpatients to say they had not seen posters, sometimes because they had not moved out of their room much or that their eyesight was poor. One or two said they had not been given any information on how to complain and that it should be provided at the outset in the information booklet.

Involvement in care planning and communication (Q5, Q6, Q8, Q19)

Only a few comments were made in relation to patient **involvement in care planning** but they provide some insights into patients' thoughts about their involvement in care. While some reiterated they were very happy with the care they received, some said that they were not really given the option to be involved, or only were because they asked for meetings with staff. One or two said they wanted more involvement, although it was recognised that this was not easy for certain patients, and that it was difficult across short inpatient stays with different care staff, or when cover for staff was not adequate. Some specific requests were made about how inpatients could be more involved and consulted, for example, have someone 'come to your home to explain what is happening to you'. It was not clear if for some people involvement was not welcome, but one inpatient commented on staff being 'over helpful and fussy'.

Inpatients were invited to comment on whether they had had the **opportunity to discuss end of life plans**. There was a range of responses from those who chose not to discuss advance care planning, and those who felt it was not the right time, to those who had discussed it or who would like to have had the opportunity. Some had discussed end of life care outside the hospice with GPs or nursing home staff. Some reported the discussions had gone well and named staff who had been particularly helpful in the process. Some said it had not come up or been discussed, and several said they would like the opportunity to talk about it, recognising it would give peace of mind to them and their relatives. A few indicated that such discussions were not easy for them, and even if they had taken place there remained uncertainties about various aspects, for example, when they subsequently had more questions about such a plan.

Inpatients were asked if they **received answers they could understand** when they had asked questions about their treatment and care. Of the comments made the majority indicated that they had received clear information, for example:

'Staff and doctors were always ready to explain anything that I did not understand'

'Caring responses in layman's terms, reassuring and helpful'

'If I wasn't sure they repeated so I could understand'

Some inpatients said they had difficulty communicating or comprehending and would use relatives to help. One or two reported difficulties with the terminology used, and a few had trouble taking in lot of information. One said that doctors were not always available to ask questions, and others said they sometimes needed more time to ask questions they thought about afterwards.

Inpatients were asked to comment on whether they received **explanations they could understand on how to take medicines** after discharge from the hospice. Some commented that they had not been discharged, illustrating that the patient survey was not being handed as intended after discharge. Most of the comments were that the information was clear and often supplied in writing. For example:

'Clear chart given me with timings of medication – very useful'

'Bit confusing... but carefully explained and an easy to understand list written out for me. Have had no problems'

Some said that explanations were not needed because they already knew how to take the medicines. Only a few comments were made that suggested there was a problem with explanations when leaving the hospice with medicines:

'Could have been explained in a much clearer and less hurried way'

'Not told what the medicine used for. Just given bag to take home to carer.'

Support and courtesy from ward and hospice staff (Q9, Q10, Q11)

When asked if ward staff made an effort to meet inpatients' **religious or spiritual needs**, the further comments written in by inpatients either said that they had no needs or that their needs were well met. People reported that the contact and conversations they had with chaplains were helpful and comforting, whether or not they shared the same religion. Several said that the subject did not come up, without indicating if this was a disappointment to them. There were three comments where people were dissatisfied: one person indicated 'it would have helped', another would have preferred to be called by his faith name rather than his legal name, and a third said that they were upset when their (lack of) belief had been questioned.

When asked about being **treated with respect and dignity** only a small number of comments were written, and these were generally very positive about the staff and the care received. A few individual incidents were mentioned when inpatients felt they were not treated with respect and dignity. These were related to a specific member of staff, and occasions when an inpatient did not like the manner in which staff spoke to them or did not welcome what they had said. There were also one or two specific complaints, such as when staff were distracted from care by other patients' demands, and when they did not close doors.

Similarly there were not a great number of comments on whether **privacy needs were met** while in the hospice, however nearly half of these related to problems with maintaining privacy. Some inpatients in rooms or wards with between two and four beds said they lacked privacy in what was said between them with staff and visitors, and others commented that curtains did not prevent private matters being overheard. There were instances of inpatients being upset or distressed at disturbances including when patients in the same ward were very sick or died, and when visitors to another patient were numerous or stayed overnight. Individual comments were made about loss of privacy when sharing a toilet, finding another patient's behaviour difficult, and not always being able to have female nurses. In contrast, one or two people would have preferred to share, finding it less lonely. The remaining comments were positive with patients saying for example:

'Although I was in a bay the staff ensured I was treated with privacy'

'The nurses are very conscious of one's need for privacy'

Hospice cleanliness, activities, general environment and catering (Q12, Q14, Q15, Q16, Q17, Q18)

On cleanliness, activities and the general environment, there were positive comments such as:

'The cleaners were lovely and very thorough'

'Noted no unpleasant smells in wards or corridors, unlike xxxx Hospital that always smells of urine. Excellent cleaning service'

'... activities in the art room were excellent'

'... the building was so bright and cheerful'

'Loved my room'

There were only four critical comments on cleanliness drawing attention to dust, cobwebs and toilet cleaning. On the general environment there were some issues with noise from building works. Other comments on the surroundings included asking for more homely touches, colourful bedding, TV and wifi in their room. Many inpatients commented that they had not taken part in activities because they were not there long enough, they were not well enough or they did not want to take part. Quite a few said they were unaware of the activities on offer. A few asked for more stimulating activities for mobile patients, including opportunities for evening socialising, more activities for men, a snooker table.

The survey asked inpatients when they **called for help if they were satisfied with the response**. Again the majority were very satisfied and praised staff, with comments like 'Staff were with you almost immediately'. About twenty comments were more critical, relating to difficulties calling staff and staff being too busy, for example:

'Call bell often out of order'

'Immobile and unable to speak – wanted help sometimes but unable to access any'

'Staff seemed very busy and sometimes left saying would come back but forgot / busy elsewhere'

'At night pain relief was slow, occasionally I felt forgotten'

The survey asked if patients had concerns that **staff were not washing their hands**. There were not many comments in total and hardly any of them were critical. Generally inpatients were impressed with hand hygiene, although quite a few said they were not concerned or did not notice.

In contrast there were many comments by inpatients when they were asked if they were **bothered by noise** while in the hospice. This was a new question in 2010/11 and it triggered scores of comments about noise disturbance. Although patients often recognised noise was inevitable in a hospice, they provided many instances when noise had bothered them. The chief sources of noise were general movements around the hospice, other patients, staff and building works. Typical comments were:

'Shoes on wooden corridor non-stop, hand towel dispenser...'

'Equipment noise during the night'

'Too many visitors'

'Very loud TV from another room'

'Other patients were in pain this was distressing to hear'

'Staff chatting very loudly, particularly at shift handover time early in the morning. Noisy trolleys'

'Banging of the door to the drugs room'

'Noisy while refurbishment work was going on'

'Building work'

There were hardly any positive comments to this question, but several acknowledged that the noise that bothered them had only happened on the odd occasion or was during the day.

Finally in this section people commented on the **catering**. There were numerous comments, the great majority of which were full of praise for the catering staff. For example:

'Beautifully cooked food – congratulations to cooks and chefs'

'All the food is excellent'

'I am unable to eat solid foods so staff very helpful with soups, ice cream, etc'

Some comments show how difficult it is to meet individual dietary preferences, for example:

'Vegetables were very over cooked'

'Vegetables were always al dente and I could not eat them'

A few of the comments were repeated by more than one person, and these were about food not being served hot enough, there being insufficient vegetables, some food was too salty / spicy, choice was a bit limited and that menus were repetitive, especially for vegetarians. Several commented that the quality and choice of food was not relevant to them as they had little appetite or were not taking food by mouth. One or two commented that it was difficult to get a hot drink after 8pm, and that catering was not good at the weekend.

When asked if they were **happy with the visiting arrangements** at the hospice, there were not many comments and most of them were positive. While some like the unrestricted visiting hours, others found that visiting areas became crowded, and that it was tiring when visitors (both their own visitors and those of other patients) arrived more than two at a time or stayed for a long while.

Overall comments (Q21)

At the end of the questionnaire inpatients were asked if they had any more comments or suggestions to help their hospice develop its services. Many inpatients took this opportunity to make remarks about their hospice stay overall, and the majority of these were favourable, sometimes repeating what has already been noted. Comments from satisfied patients included:

'I found the hospice a total surprise in all aspects in a very pleasing way. The staff are friendly, helpful and professional in every way'

'I do not think you can improve on the services at xxx. It is a wonderful place with really wonderful staff. When I arrived I thought I was already in heaven'

'In my opinion it cannot be improved as the standard is excellent'

'If I were dying, I would like to die at xxxx, it is the best place I have ever been and all the staff are the best I've known. They made me very happy'

While some reiterated comments they had made earlier, a few patients raised new issues or made a new suggestion at this point in the questionnaire. There were a few comments about improving bathrooms (less sharing, better hand-grips and walk-in showers), and parking facilities. Four or five people asked for better and more frequent communication with medical staff, and making sure carers were included. Suggestions made by only one person included having a lights/TV out policy, using volunteers to serve drinks when short-staffed, access to counselling. One of the inpatients who was distressed when in close proximity to others who were dying suggested that respite patients were put together. Finally, one comment pointed out that the heavy snowfalls in December 2010 had accounted for some of the complaints about low staffing levels.

The Questionnaire (Q22)

There were quite a few positive comments that the survey was clear, straightforward and covered all the main topics, and a few comments suggesting improvements or changes. One or two found it long, boring or confusing. It was suggested that when a relative or carer had completed the questionnaire on the patient's behalf that the questionnaire could be changed slightly to accommodate this and make it clear who was responding.

Some people asked for more questions and more space to write in comments. Some pointed out when questionnaires had been incorrectly put together, and one or two found the question on hand-washing poorly worded.

5. Summary of Findings

In 2010/11 substantial improvements were made to the survey to reflect current and future priorities for hospices. This process was undertaken by the Help the Hospice Patient Survey Group, which contained representatives from hospices, academics and Help the Hospices and aimed to ensure changes meet practical and methodological requirements. Some new topics and questions have been added to the survey, while others deemed as a lower priority have been omitted.

Fewer hospices took part compared to previous years, but there were more responses per hospice, a higher response rate for inpatients and more daycare services were included in benchmark figures. Aggregated results for the benchmark hospices and all participating hospices overall were very positive for both the daycare and inpatient ward settings, with services being considered excellent and of a high standard in a number of areas. Similar to the previous survey, the highest praise was shown for the staff that worked in the hospice, with the vast majority of respondents saying that they always had confidence in the staff caring for them, that they were always treated with respect and dignity, and that staff always made an effort to meet patients' individual privacy needs. There were also high ratings for care staff introducing themselves and explaining what they were doing.

For inpatient services, there were high levels of satisfaction with the visiting arrangements, knowing how to call for help and the response they got when help was needed. Daycare patients were very satisfied with the number of staff and volunteers around.

For both services, patients were highly complimentary about information leaflets and booklets provided by hospices to patients about their services, in terms of their helpfulness, being accurate and easy to understand. However, only two thirds of respondents overall were aware of such leaflets, with this proportion falling to just over half for inpatients in the benchmark hospices. The proportion of daycare patients who said they were aware of the leaflets has improved.

Cleanliness of hospices and the general environment were rated highly, and around two thirds of the patients were always satisfied with transport and food. Survey respondents provided many comments on these two topics, and although the great majority were positive, they also contained views and suggestions that hospices will be able to consider when planning future services.

Satisfaction levels were broadly similar for inpatients and daycare patients, although there were differences in some areas. Satisfaction was higher for inpatients in the following topics: there were fewer daycare patients compared to inpatients who were satisfied with their involvement in planning care, fewer daycare patients said they had the opportunity to discuss their wishes for end of life care, and to ask questions about their care. Satisfaction for inpatients was lower in relation to noise, as they were much more bothered by noise compared to daycare patients. The sources of noise disturbance during their time in the hospice have been described in respondents' comments, and hospices may wish to address some of these.

Topics with the lowest survey ratings were the low proportions (half or less) who had been involved in advanced care planning discussions, and who had seen notices about how to complain. Ratings of staff's efforts to meet religious and spiritual needs, satisfaction with the activities available were also lower than other parts of the survey response. Some of these lower ratings were due to the number of patients who did not want to be involved in these areas, for example, those who said it was not the appropriate time to have end of life discussion, those who had no need to complain, had no religious or spiritual needs, and those did not want to take part in activities. Nevertheless, the comments on the range of activities available, especially within daycare services should be noted as an area whereby there could be a wider variety of activities in order to cater for different interests.

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

The results for benchmark hospices were very similar to the average results for all hospices for daycare. The survey showed that hospices have become more similar in patients' satisfaction ratings, and that the variation between the best and the worst has become narrower. However variation remains in patients' views on transport services and catering.

Variability in the results for the inpatient results may be due to the lower number of hospices being included in the benchmark figures. If the characteristics of individual benchmark hospices were either rated particularly satisfactory or unsatisfactory then they have more of an impact on the average results. Low numbers in the inpatient benchmark indicates that reaching a response of 40 or more completed questionnaires was harder to achieve within the inpatient units of the hospices that participated in the survey this year.

Some comparison was made between the results for the 2010/11 survey and the previous survey in 2008/09. Overall satisfaction with daycare and inpatient services remains extremely high, with improvements in the information seen by daycare patients, and staff introducing themselves. However there has been a decline in the opportunities patients felt they had for asking questions, and in their ratings of the hospice environment generally. The difficulty with such a comparison of the benchmark results in particular is that year on year different hospices participate and the number of hospices achieving the benchmark will vary and this needs to be taken into account when interpreting the results over time.

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

6. Considerations for the Future

- This survey has been substantially improved and updated and used a fourth time to seek views of patients on the quality of the treatment and care provided as required by the Care Quality Commission. Given the similar nature of the results overall to previous years there is growing confidence in these results and the trends seen in patient satisfaction.
- Individual hospices participating in the survey can use the results to measure change in their quality of care over time, as well as being presented with benchmark figures to alert them to issues more widely regarding patient satisfaction with hospice care.
- The survey results allow hospices taking part them to legitimately identify areas for improvement in their hospice and take appropriate action. Hospices may wish to discuss them when making strategic and organisational plans. They may also wish to undergo further investigations of particular issues by consultation with patients, for example using more qualitative methods of research, such as focus groups or meetings with patients and staff to discuss an issue.
- While the surveys have shown high levels of satisfaction for daycare and inpatient services, they also help to indicate areas with less high ratings, such as involvement in planning care, being able to ask questions and discuss wishes for end of life care. Participating hospices should be encouraged to develop their own action plans where there is scope for improvement, identified from their individual results.
- Further consideration will be given to the survey's future shape to reflect emerging issues and priorities relating to patient satisfaction.

Hospice Code

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

Many thanks for your time.

1. During your time in day care at [enter name of hospice here], were you aware of a leaflet or booklet called [enter name of information here]?

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

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

A. Was the leaflet or booklet easy to understand?

- No Can't remember
 Yes Did not look at the leaflet or booklet

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

B. Was the leaflet or booklet helpful?

- No Can't remember
 Yes Did not look at the leaflet or booklet

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

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

- No Can't remember
 Yes Did not look at the leaflet or booklet

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

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

**2. Did you feel anxious at the beginning of your first visit to day care?
(Please tick the box closest to your view.)**

- Very anxious
- Anxious
- Not at all anxious

**3. Did you feel anxious at the end of your first visit to day care?
(Please tick the box closest to your view.)**

- Very anxious
- Anxious
- Not at all anxious

4. Was there anything more we could have done to make you feel less anxious?

5. Did you use transport organised by the hospice?

- No Please go to question 7.
- Yes Please go to question 6.

6. If you used hospice transport, please rate the following by ticking the appropriate box.

	Poor	Acceptable	Good	Excellent
Whether you were picked up on time				
Comfort of the journey				
Safety of the journey				

Do you have any further comments on the hospice transport?

While you were in day care at **[enter the name of the hospice here]**:

7. Did the staff involved in your care introduce themselves?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

8. Did the staff involved in your care explain what they were doing?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

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

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

10. How satisfied were you with how involved you were in planning your care?

Not at all satisfied <input type="checkbox"/>	Not satisfied <input type="checkbox"/>	Satisfied <input type="checkbox"/>	Very satisfied <input type="checkbox"/>
--	---	---------------------------------------	--

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

11. Have you had the opportunity to discuss your wishes for future care up until the end of your life (advanced care planning)?

No
Yes
Do you have any further comments?

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

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>	Did not ask any questions <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------	---

13. When you had questions to ask about your treatment and care in day care, did you receive answers that you could understand?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>	Did not ask any questions <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------	---

Do you have any further comments?

14. Did you feel confident that there were enough staff or volunteers in day care to offer help if needed?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

15. Did you feel day-care staff made an effort to meet your religious or spiritual needs?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

16. Were you treated with respect and dignity in day care?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

17. Did you feel your privacy needs were met in day care?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

18. Please rate the following by ticking the appropriate box.

	Poor	Acceptable	Good	Excellent
How clean you found the hospice				
Activities available for you to take part in				
The general environment and surroundings				

Do you have any further comments?

19. While in day care, did you have any concerns that staff were not washing their hands?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>	Did not notice <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------	--

Do you have any further comments?

20. Were you bothered by noise while in day care?

- Often
- Occasionally
- Never

If you were, it would be helpful to give details.

21. Were you satisfied with the following? (Please tick.)

	Never	Sometimes	Most of the time	Always
The quality of the food				
The choice of food available				

Do you have any further comments?

22. While in day care did you see any notices, posters or leaflets explaining how to complain about the care or treatment you received?

- No
Yes

Do you have any further comments?

23. Do you have any more comments or suggestions to help us develop our day-care services? Please write below.

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

DAYCARE QUESTIONNAIRE
Hospice Code

You can get the results of this survey (and any action we have taken as a result of patients' answers) from [Enter the appropriate details for your hospice].

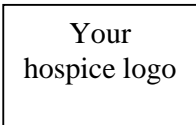
Please return the filled-in survey in the prepaid envelope or send it to:

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

If you feel we could learn from hearing more about any part of your care you were not entirely satisfied with or that you found particularly helpful, please call [enter details of daycare clinical manager here].

Thank you again for your help.





Hospice Code

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

Many thanks for your time.

1. During your time at [enter name of hospice here], were you aware of a leaflet or booklet called [enter name of information here]?

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

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

A. Was the leaflet or booklet easy to understand?

- No Can't remember
- Yes Did not look at the leaflet or booklet

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

B. Was the leaflet or booklet helpful?

- No Can't remember
- Yes Did not look at the leaflet or booklet

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

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

- No Can't remember
- Yes Did not look at the leaflet or booklet

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

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

While you were in [enter the name of the hospice here]:

2. Did the staff involved in your care introduce themselves?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

3. Did the staff involved in your care explain what they were doing?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

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

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

5. How satisfied were you with how involved you were in planning your care?

Not at all satisfied <input type="checkbox"/>	Not satisfied <input type="checkbox"/>	Satisfied <input type="checkbox"/>	Very satisfied <input type="checkbox"/>
--	---	---------------------------------------	--

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

6. Have you had the opportunity to discuss your wishes for future care until the end of your life (advanced care planning)?

- No
Yes

Do you have any further comments?

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

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

8. When you had questions to ask about your treatment and care, did you receive answers that you could understand?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>	Did not ask any questions <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------	---

Do you have any further comments?

9. Did you feel ward staff made an effort to meet your religious or spiritual needs?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

10. Were you treated with respect and dignity in the hospice?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

11. Did you feel your privacy needs were met in the hospice?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------

Do you have any further comments?

12. Please rate the following by ticking the appropriate box.

	Poor	Acceptable	Good	Excellent
How clean you found the hospice				
Activities available for you to take part in				
The general environment and surroundings				

Do you have any further comments ?

13. Did you know how to call for help?

- No
Yes

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

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>	Did not need to call for help <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------	---

Do you have any further comments?

15. While on the ward did you have any concerns that staff were not washing their hands?

Never <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Most of the time <input type="checkbox"/>	Always <input type="checkbox"/>	Did not notice <input type="checkbox"/>
-----------------------------------	--	--	------------------------------------	--

Do you have any further comments?

16. Were you bothered by noise in the hospice?

- Often
Occasionally
Never

If you were, it would be helpful to give details.

17. Were you satisfied with the following? (Please tick.)

	Never	Sometimes	Most of the time	Always	Did not apply to me
The quality of the food					
The choice of food available					
Access to food between mealtimes, including during the night					

Do you have any further comments?

18. Were you happy with the visiting arrangements at the hospice?

No
Yes

If 'No', it would be helpful to us if you can explain why.

19. When you were discharged, did our staff explain how to take your medicines in a way that you could understand?

No
Yes

Do you have any further comments?

20. While in the hospice did you see any notices, posters or leaflets explaining how to complain about the care or treatment you received?

- No
Yes

Do you have any further comments?

21. Do you have any more comments or suggestions to help us develop our inpatient services?

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

You can get the results of this survey (and any action we have taken as a result of patients' answers) from [\[Enter the appropriate details for your hospice\]](#).

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

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

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

Thank you again for your help.



APPENDIX C

Questionnaire Amendments – 2010/11 Survey

A number of amendments were made to questions for the 2010/11 survey at meetings of the Help the Hospice Patient Survey Group, and with the approval of the Plain English Campaign. The tables below show the correspondence between questions in this and the previous survey, and where changes have been made.

Day Care Questionnaire

2008/09 question number	2008/09 Survey	2010/2011 question number	2010/11 Survey
Q1,Q2		Q1	
Q3		Q2	Change in response scale, dropped 'Can't remember'
Q4		Q3	Change in response scale, dropped 'Can't remember'
Q5		Q4	Minor re-word
Q6		Q5	
Q7		Q6	Minor re-word, change in response scale
Q8a		Q7	
Q8b		Q8	Minor re-word
Q9		Q9	
Q10		Q10	Minor re-word, minor response scale change
		Q11	New question added: Have you had the opportunity to discuss your wishes for future care up until the end of your life (advanced care planning)?
Q12a	How supported did you feel when a group member had been discharged?		Dropped
Q12b	How supported did you feel when a group member had died?		Dropped
Q13		Q12	
Q11		Q13	Minor re-word
Q19		Q14	Response layout change
		Q15	New question added: Did you feel day-care staff made an effort to meet your religious or spiritual needs?
Q14	Did you feel staff made an effort to meet your individual needs and wishes?		Dropped
Q15-Q16		Q16-Q17	Minor re-word, response layout change
Q18		Q18	Change in response scale, catering question moved to q21
		Q19	New question added: While in day care, did you have any concerns that staff were not washing their hands?
		Q20	New question added: Were you bothered by noise while in day care?
Part of Q18		Q21	Minor re-word, change in response scale. New item added: The choice of food available
Q17		Q22	Re-worded
Q19	Did you feel confident that there were enough staff or volunteers around to offer help if needed?		Dropped
Q20		Q23	
Q21		Q24	

In-patient Questionnaire

2008/09 question number	2008/09 Survey	2010/2011 question number	2010/11 Survey
Q1,Q2		Q1	
Q3a		Q2	Response layout change
Q3b		Q3	Response layout change
Q4		Q4	Response layout change, minor re-word on comments
Q5		Q5	Minor re-word, response layout change
Q8	Did you have enough time to make decisions about your care?	Q6	New replacement question: Have you had the opportunity to discuss your wishes for future care until the end of your life (advanced care planning)?
Q7		Q7	
Q6		Q8	Minor re-word
		Q9	New question added: Did you feel ward staff made an effort to meet your religious or spiritual needs?
Q9	Did you feel staff made an effort to meet your individual needs and wishes?		Dropped
Q10-Q11		Q10-Q11	Minor re-word, comment added
Part of Q13		Q12	Change in response scale. New item added: Activities available for you to take part in
Q14		Q13	Minor re-word
Q14a		Q14	Comment added
Q15	How supported did you feel if a patient died while you were in the hospice?		Dropped
		Q15	New question added: While on the ward did you have any concerns that staff were not washing their hands?
		Q16	New question added: Were you bothered by noise in the hospice?
Part of Q13		Q17	New question added: Were you satisfied with the following? Access to food between mealtimes, including during the night
		Q18	New question added: Were you happy with the visiting arrangements at the hospice?
		Q19	New question added: When you were discharged, did our staff explain how to take your medicines in a way that you could understand?
Q12		Q20	Re-worded, comment added
Q16		Q21	Minor re-word
Q17		Q22	

APPENDIX D

Response Statistics – All Help the Hospices Patient Surveys

		2004/05	2006/07	2008/09	2010/11
No. of hospices participating	All hospices	53	53	52	39
	All Daycare	50	49	46	37
	All Inpatient	46	48	46	35
	Both services	43	44	40	33
	Just Daycare	7	5	6	4
	Just Inpatient	3	4	6	2
Returned questionnaires	Daycare	1398	1352	1259	1150
	Inpatient	926	1052	963	834
	Total	2324	2404	2222	1984
Average no. returns per hospice (min-max)	Daycare	28 (3-59)	28 (8-53)	27 (4-60)	31 (2-57)
	Inpatient	20 (4-59)	22 (2-58)	21 (2-56)	24 (6-46)
Response rate	Daycare	-	61% (from 28 hospices)	62% (from 25 hospices)	62%*
	Inpatient	-	49% (from 29 hospices)	41% (from 25 hospices)	45%*
Number reaching the benchmark	Daycare	13	10	9	13
	Inpatient	5	9	4	4
Data collection period		7 months	8 months	8 months	8 months

* In 2010/11 the average daycare response rate excludes hospice IDs 38d and 98d, and average inpatient response rate excludes hospice IDs 56i and 104i, where data on number of surveys handed out was incomplete

APPENDIX E

Help the Hospices Patient Survey 2010/11 Final number of returned questionnaires - 20th June 2011

Hospice Name	Daycare services	Inpatient services	Total
Trinity Hospice and Palliative Care Services - Blackpool	N/A	16	16
Hospiscare – Exeter	49	30	79
North Devon Hospice – Barnstaple	28	8	36
Dorothy House Hospice Care - Bradford on Avon	41	36	77
Halton Haven Hospice – Runcorn	10	11	21
St Catherine's Hospice - CRAWLEY, West Sussex	24	34	59
St Andrew's – Grimsby	32	9	41
St. Ann's Hospice - Cheadle, Cheshire	56	29	86
St Catherine's Hospice - Nr Preston	40	19	58
St John's Hospice – Lancaster	20	32	52
St John's Hospice in Wirral	31	29	60
St John's Hospice – London	19	17	36
St Richard's Hospice – Worcester	32	17	49
St Margaret's Somerset Hospice - Taunton	32	12	44
Wigan and Leigh Hospice – Wigan	20	19	39
St Luke's Hospice (Harrow and Brent) – Harrow	20	16	36
Hospice in the Weald - Tunbridge Wells, Kent	45	39	84
Meadow House Hospice – Middx	27	26	53
Pilgrims Hospices in East Kent – Ashford	49	46	95
Southern Area Hospice Services – NEWRY	22	22	44
St Luke's Hospice – Sheffield	52	28	80
Willowbrook Hospice – PRESCOT	30	22	52
Highland Hospice – Inverness	29	14	43
EllenorLions Hospices – Kent	45	17	62
Great Oaks Dean Forest Hospice – Gloucestershire	12	N/A	12
East Cheshire Hospice - Macclesfield Cheshire	8	12	20
Greenwich and Bexley Cottage Hospice - London	45	25	70
Weldmar Hospicecare Trust - Dorchester, Dorset	35	34	69
The Myton Hospices – Warwick	44	46	90
Weston Hospicecare - Uphill, Weston-super-Mare	20	N/A	20
St. Joseph's Hospice – London	15	31	46
Mary Stevens Hospice – DUDLEY	49	6	55
Cynthia Spencer Hospice - Northampton	N/A	42	42
Kemp Hospice – Worcestershire	37	N/A	37
Pembridge palliative care centre - London	2	13	15
Salisbury Hospicecare Trust - Salisbury	8	13	21
St Elizabeth Hospice - Ipswich	41	N/A	41
St Wilfrid's Hospice - Eastbourne	33	41	74
Strathcarron Hospice - Denny, Stirlingshire	47	23	70
Total returned	1150	834	1984