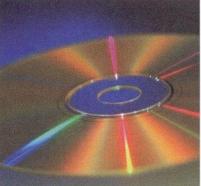




Results of the 2012/2013 Hospice Patient Survey

General Report









Linda Jenkins and Jan Codling

November 2013





Hospice UK. Company limited by guarantee. Registered in England & Wales No 2751549. Charity registered in England & Wales No 1014851 & Scotland No SC041112.

Help the Hospices has changed its name to Hospice UK

This resource was published prior to the change and so still refers to the old name

Results of the 2012/2013 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 Stephen Peckham 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-.

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

Researchers in the Centre attract funding of nearly £l 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:

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

Tel: 01227 824057

E-mail: d.arthurs@kent.ac.uk

Fax: 01227 827868 www.kent.ac.uk/chss

Contents

Acknowledgements

	Page
Executive Summary	1
1. Introduction	2
2. Methods	3
3. Results: Daycare	5
3.1 Individual Hospice Daycare Results (only in individual hospice reports)3.2 All Hospices Daycare Results (19 hospices)	5 5
4. Results: Inpatient	22
4.1 Individual Hospice Inpatient Results (only in individual hospice report)4.2 All Hospices Inpatient Results (18 hospices)	22 22
5. Summary of Findings, Comments and Trends over time	37
6. Considerations for the Future	40

- Appendices : A Daycare questionnaire
- B Inpatient questionnaire
 C Response statistics across all Help the Hospices Patient Surveys
 D Number of questionnaires handed out and returned
 E Trends in average results from 2004/5 to 2012/13

Acknowledgements

We would like to thank Help the Hospices and the 20 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.

Executive Summary

The 2012/13 survey is the fifth 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, 2008/09 and 2010/11. All hospices across the UK were invited to take part in the 2012/13 Patient Survey and 20 hospices participated between November 2012 and May 2013.

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 1039 replies, 574 from daycare users and 465 from inpatients. Response rates were 64% for daycare patients, and 50% for inpatients, which was an increase on the last survey response especially from inpatients. Results are shown separately for the two services, and the report gives the average results for all hospices.

2012/13 survey results showed that patients continued to rate various aspects of hospice care very highly, such as being treated with respect and dignity, with sensitivity to their privacy, and patients expressed high levels of confidence in staff. Daycare patients' ratings were largely the same as the previous survey, but were significantly higher for having the opportunity to discuss advanced care plans, as well as the range of activities and food on offer. Inpatient satisfaction increased compared to the previous survey for many areas and significantly so for cleanliness, activities available, disturbance from noise, food quality, and visiting arrangements. While these changes are encouraging to see, the fact that each survey contains a different cohort of hospices means that no firm conclusions can be drawn about these improvements without looking at hospices individually.

Patient satisfaction levels remained remarkably consistent over the five surveys from 2004 to date and any changes have been quite small. Over the series there have been notable improvements in the provision of information and in reducing anxiety of daycare patients, while satisfaction has fallen for some aspects of patient transport.

Inevitably there remain some areas in the survey where significant proportions of patients are not fully satisfied and where results for hospices vary. These topic areas include the provision of information for patients and the way staff communicate, especially in creating opportunities for advanced care planning when these are wanted and recognising where patients have particular religious or spiritual needs. It is recommended that participating hospices develop their own action plans where there is scope for improvement, identified from their individual results.

This survey may serve as the last in its current form, given the many additional opportunities that are beginning to emerge to engage users of hospices in discussion regarding their experience of care and how they would suggest it is improved. It has served a valuable role in listening to the views of patients who receive inpatient or day care from hospices and we are most grateful to the many hospices and their patients that have taken part in it the last 10 years and have supported its development.

1. Introduction

Welcome to the fifth 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 20 Hospices that participated in the survey between 1st November 2012 and 31st May 2013.

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 over the years 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 three 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 current version includes questions on hand hygiene, noise levels, advance care planning, information on medications at discharge and hospice visiting arrangements to reflect more recent 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). It gives the opportunity for each hospice to compare their results with other hospices, and it shows trend data since the series began.

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.

2. Methods

The 2012/13 survey is the fifth 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, 2008/09 and 2011/11. 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). This year there were no amendments to the survey questions.

All hospices across the UK were invited to take part in the 2012/13 Patient Survey. 20 hospices participated in the survey, with 19 of these hospices participating in daycare and 18 in the inpatient survey. Most hospices participated in both surveys, with the remainder surveying one service. This time 17 hospices distributed questionnaires to both daycare services and inpatient services, 2 distributed questionnaires to patients using daycare services only, and 1 hospice distributed to inpatient services only.

Survey materials were distributed by Help the Hospices. 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 guidance asked that the survey was distributed to all adult patients using inpatient and/or daycare services in the participating hospices. 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.

The time frame for distribution and return of questionnaires was scheduled for seven months, between November 2012 and May 2013. 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. It was recommended that 40 or more completed questionnaires should be returned from one or both services in order to be confident in the results. Previous surveys had used this as a benchmark to include hospices in comparative figures, but this excluded the majority of hospices and over time we have seen the average for benchmark hospices to be very similar to the average of all hospices. This year the General Report shows the average for all hospices, and individual hospice reports show each hospice against this average. It should be noted that the confidence intervals around the results for small hospices or those that received considerably fewer than 40 replies will be wide.

Despite the lower number of hospices taking part the number of questionnaires returned for inpatient services was 465, and 574 from daycare services. Compared to the previous survey fewer hospices took part, but in 2012/13 response rates were improved, especially for inpatients (Appendix C). For the actual numbers returned by individual participating hospices see Appendix D. 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. All hospices kept records enabling response rates to be calculated (however for one inpatient service there was a problem with recording the number of surveys handed out and it was excluded from response rate averages). The overall response rate for the survey was 64% for daycare based on 19 hospices and 50% for inpatient based on 17 hospices. (Appendix C).

The collected data was entered and analysed, generating descriptive statistics, using SPSS software version 21 (Statistical Package for the Social Sciences). Open ended and textual comments were typed in verbatim and supplied to each hospice as in previous years, but this year are only briefly summarised in section 5.

palliative-care-directory-20122013/ Accessed 21 October 2013.

_

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/media-centre/latest-news/hospice-and-

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 All Hospices Daycare Results (19 hospices)

For the first time all hospices are included in average figures irrespective of the number of responses, so the results represent the views of all 574 daycare patients in the survey. This section of the report gives an overview of the aggregate results in tables and charts 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 aggregated average patient responses (counts and percentages) from all nineteen hospices aggregated together. The range of results (minimum and maximum of the individual hospices) are also reported. By including all hospices in this section, rather than just those with at least 40 responses, average figures are comparable with previous reports, but it does lead to much wider ranges between minimum and maximum values due to the inclusion of hospices with only a handful of responses. The aggregated average results displayed in these tables are then reported visually in a bar-chart for each question.

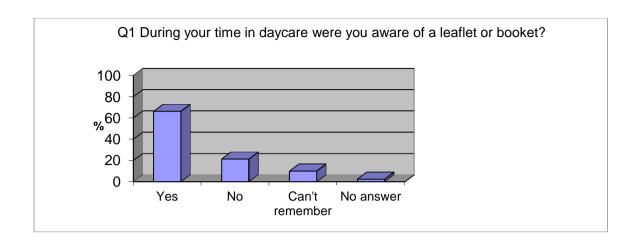
Any notable differences (of -/+5% or more) since the 2010/11 survey are reported in the written commentary. However different groups of hospices taking part in both surveys make it difficult to interpret how meaningful such comparisons of similarities or differences are. In 2012/13 there was a small but widespread increase in the proportion of people answering each question, which suggests an increasing willingness of patients to give their view about sensitive topics.

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.

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

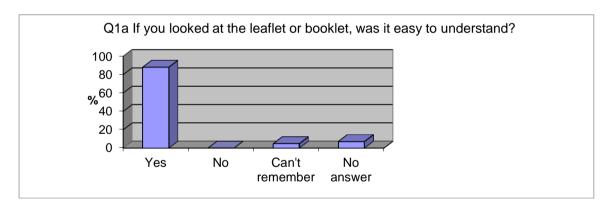
	N	Average (%)	Range (%)
Yes	380	66.2	36.2 – 87.5
No	122	21.3	7.5 - 46.7
Can't remember	58	10.1	0.0 – 28.3
No answer	14	2.4	0.0 – 7.7
Total	574	100	



Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on daycare services. A few people said they had not looked at it.

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

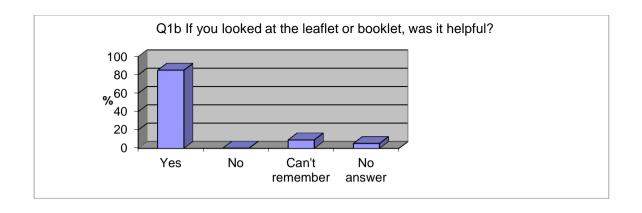
	N	Average (%)	Range (%)
Yes	332	88.1	62.5 – 100.0
No	0	0.0	0.0 - 0.0
Can't remember	18	4.8	0.0 – 20.0
No answer	27	7.2	0.0 – 28.6
Total	377	100	
Did not look at the leaflet or bo	oklet: 17		
Not applicable: 180			



The proportion who said the information booklet was helpful fell from 90% in 2010/11 to 85% in this survey.

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

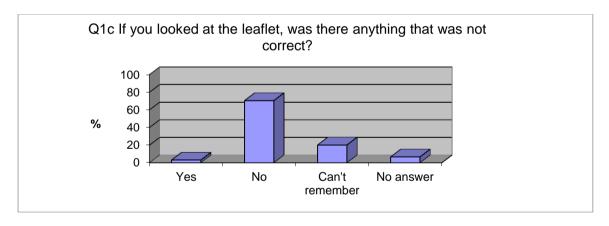
and it you looked at the loanet of booklot, was it helpful.				
	N	Average (%)	Range (%)	
Yes	320	85.1	57.1 – 100.0	
No	1	0.3	0.0 - 2.9	
Can't remember	35	9.3	0.0 - 28.0	
No answer	20	5.3	0.0 - 28.6	
Total	376	100		
Did not look at the leaflet or be	ooklet: 18			
Not applicable: 180				



Comments on incorrect information and suggestions of more information to include in the leaflet are given in individual hospice reports and all textual comments are briefly summarised in section 5 of this report.

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

	N	Average (%)	Range (%)	
Yes	11	2.9	0.0 – 8.1	
No	266	70.4	48.0 – 100.0	
Can't remember	76	20.1	0.0 - 36.0	
No answer	25	6.6	0.0 – 42.9	
Total	378	100		
Did not look at the leaflet or booklet: 16				
Not applicable: 180				



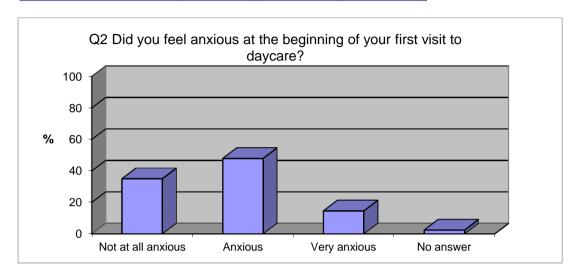
Anxiety on first daycare visit

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.

Compared to 30% in 2010/11, a larger proportion of people in 2012/13 (35%) said they were not at all anxious at the beginning of their first day. As in previous years the questions showed that respondents were much less anxious at the end of their first visit.

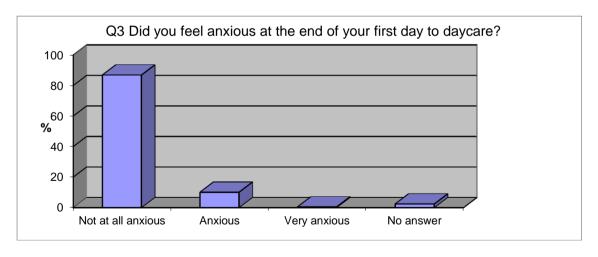
Q2 Did you feel anxious at the beginning of your first visit to daycare?

	N	Average (%)	Range (%)
Not at all anxious	201	35.0	11.8 – 50.0
Anxious	275	47.9	39.1 – 75.0
Very anxious	84	14.6	0.0 - 33.3
No answer	14	2.4	0.0 - 7.7
Total	574	100	



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

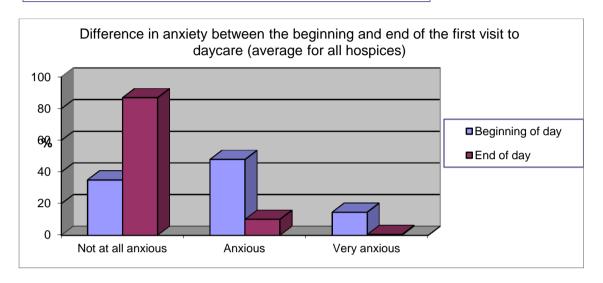
•	N	Average (%)	Range (%)
Not at all anxious	499	86.9	73.9 – 100.0
Anxious	58	10.1	0.0 – 25.0
Very anxious	3	0.5	0.0 - 2.7
No answer	14	2.4	0.0 - 7.7
Total	574	100	



Results on change in anxiety for all hospices are shown for patients who answered both of the questions on anxiety before and after their first visit to daycare. Respondents were asked to write down if their hospice could have done anything to help relieve their anxiety on their first visit.

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

,	N	Average (%)	Range (%)
1	1.1		
Less anxious	331	57.7	37.5 – 76.5
No change	225	39.2	23.5 – 52.2
More anxious	3	0.5	0.0 – 12.5
No answer	15	2.6	0.0 – 7.7
Total	574	100	
Missing answers: 0			

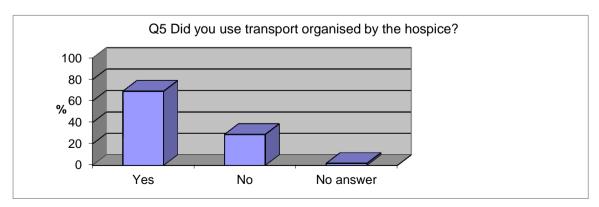


Use of transport by daycare patients

These questions apply to daycare patients who used transport organised by the hospice. Further comments made by respondents on hospice transport can be found in individual hospice reports and briefly summarised in section 5 of this report. While ratings for punctuality and comfort of hospice transport have been falling since 2004/5, there were no significant changes between 2010/11 and 2012/13.

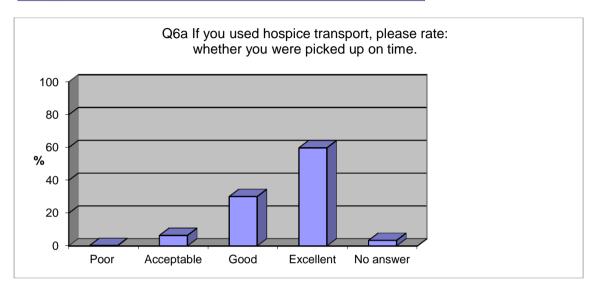
Q5 Did you use transport organised by the hospice?

	N	Average (%)	Range (%)
Yes	397	69.2	30.3 – 100.0
No	166	28.9	0.0 - 69.7
No answer	11	1.9	0.0 - 7.7
Total	574	100	



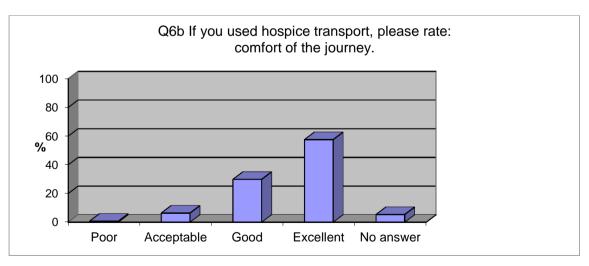
Q6a If you used hospice transport, please rate: whether you were picked up on time.

	N	Average (%)	Range (%)
Poor	1	0.2	0.0 – 33.3
Acceptable	26	6.4	0.0 – 25.0
Good	123	30.1	9.1 – 70.0
Excellent	244	59.8	33.3 – 87.9
No answer	14	3.4	0.0 – 15.4
Total	408	100	
Not applicable: 166			



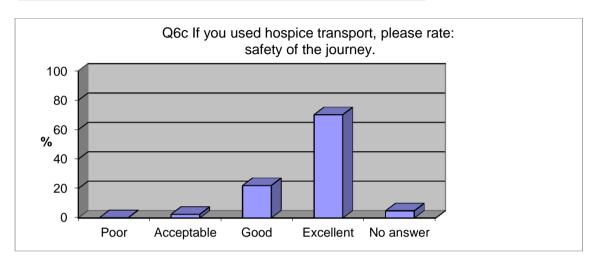
Q6b If you used hospice transport, please rate: comfort of the journey

	N	Average (%)	Range (%)
Poor	3	0.7	0.0 – 10.0
Acceptable	26	6.4	0.0 - 33.3
Good	122	29.9	12.1 – 60.9
Excellent	235	57.6	20.0 - 83.3
No answer	22	5.4	0.0 – 14.3
Total	408	100	
Not applicable: 166			



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

			
	N	Average (%)	Range (%)
Poor	1	0.2	0.0 - 7.7
Acceptable	10	2.5	0.0 - 33.3
Good	90	22.1	0.0 – 37.5
Excellent	287	70.3	33.3 – 92.3
No answer	20	4.9	0.0 – 20.0
Total	408	100	
Not applicable: 166		·	



Daycare staff: communication and care

The survey asked patients about the communication and care they had received from staff in daycare. The proportion that said staff always introduced themselves has gone down from 84% in 2012/11 to 79%. Confidence in staff remains at a high level.

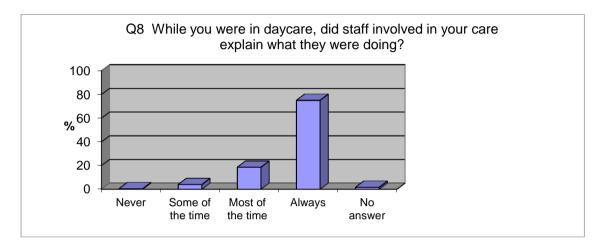
Q7 While you were in daycare, did the staff involved in your care introduce themselves?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 12.5
Some of the time	15	2.6	0.0 – 13.3
Most of the time	97	16.9	0.0 - 33.3
Always	452	78.7	53.3 – 100.0
No answer	9	1.6	0.0 - 7.7
Total	574	100	



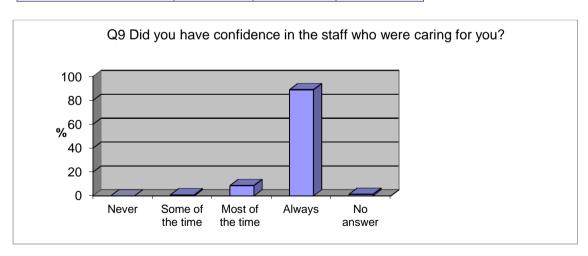
Q8 While you were in daycare, did staff involved in your care explain what they were doing?

	N	Average (%)	Range (%)
Never	3	0.5	0.0 – 12.5
Some of the time	23	4.0	0.0 - 33.3
Most of the time	107	18.6	0.0 - 33.3
Always	431	75.1	33.3 – 91.7
No answer	10	1.7	0.0 - 7.7
Total	574	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	0.9	0.0 - 6.7
Most of the time	50	8.7	0.0 - 25.0
Always	511	89.0	73.1 – 100.0
No answer	8	1.4	0.0 – 7.7
Total	574	100	



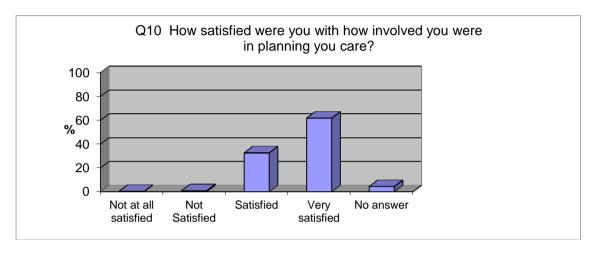
Daycare user involvement and understanding

Patients were asked about their overall satisfaction with their involvement in the planning of their care while in daycare. The proportion who were very satisfied went up from 57% in 2010/11 to 62%. 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.

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

	N	Average (%)	Range (%)
Not at all satisfied	2	0.3	0.0 - 2.5
Not satisfied	5	0.9	0.0 - 6.7
Satisfied	187	32.6	0.0 – 66.7
Very satisfied	355	61.8	33.3 – 100.0
No answer	25	4.4	0.0 – 13.3
Total	574	100	



The next question was about having the opportunity to discuss wishes for future care up until end of life, in other words asking about advanced care planning. There was a large increase in the proportion of patients who had been given the opportunity for a discussion, from 43% in 2010/11 to 56% in 2012/13.

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

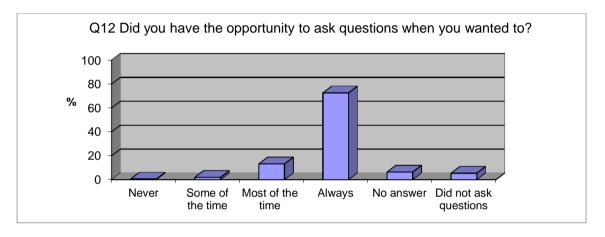
,	N	Average (%)	Range (%)
Yes	324	56.4	19.2 – 100.0
No	204	35.5	0.0 – 73.1
No answer	46	8.0	0.0 – 16.7
Total	574	100	



As has been found in previous surveys respondents were positive in their views on the communication with staff more generally, for example about being given the opportunity to ask questions when they wanted to.

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

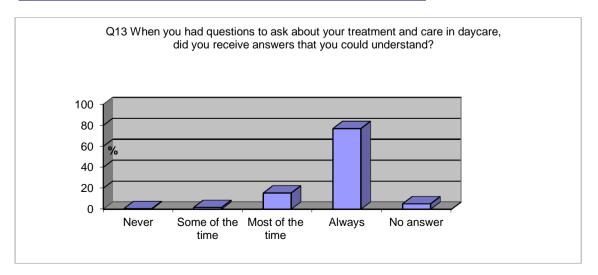
			
	N	Average (%)	Range (%)
Never	3	0.5	0.0 - 6.7
Some of the time	11	1.9	0.0 – 12.5
Most of the time	76	13.2	0.0 – 23.9
Always	417	72.6	53.8 – 100.0
No answer	36	6.3	0.0 – 23.1
Did not ask any questions	31	5.4	0.0 – 14.5
Total	574	100	



The survey went on to ask users if they understood the explanations given to them about their care while in daycare. Comments were invited on how well explanations were understood.

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	3	0.6	0.0 - 6.7
Some of the time	9	1.7	0.0. – 6.7
Most of the time	83	15.5	0.0 – 37.5
Always	414	77.1	50.0 – 100.0
No answer	28	5.2	0.0 – 15.4
Total	537	100	
Did not ask any questions: 37			



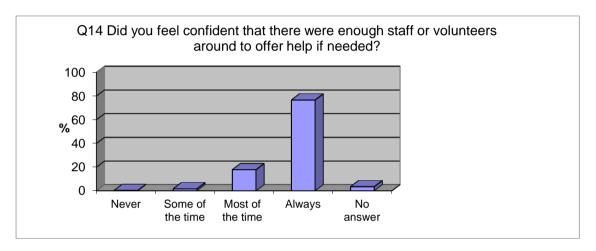
Views of users on the support and courtesy from daycare staff

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.

The first question asked their view on the number of staff and volunteers working in their hospice.

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

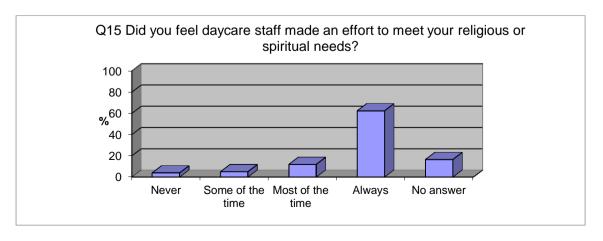
	N	Average (%)	Range (%)
Never	2	0.3	0.0 - 3.8
Some of the time	10	1.7	0.0 - 6.7
Most of the time	102	17.8	0.0 – 34.6
Always	440	76.7	57.7 – 100.0
No answer	20	3.5	0.0 – 17.6
Total	574	100	



The next question was about whether daycare staff made an effort to meet religious or spiritual needs. The comments suggested that guite 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?

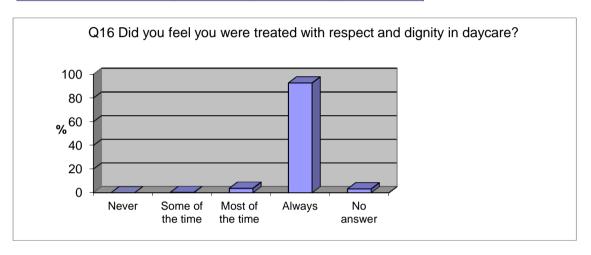
	N	Average (%)	Range (%)
Never	23	4.0	0.0 - 37.5
Some of the time	29	5.1	0.0 – 13.3
Most of the time	69	12.0	0.0 - 25.0
Always	358	62.4	33.3 – 100.0
No answer	95	16.6	0.0 - 34.8
Total	574	100	



The vast majority of daycare patients felt they were always treated with respect, and that their privacy needs were always met.

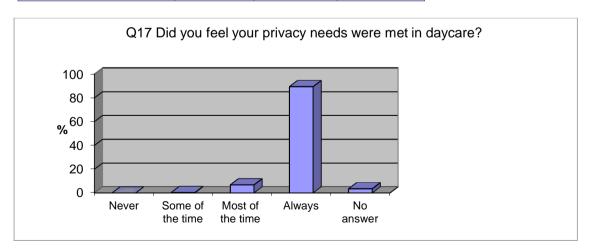
Q16 Did you feel you were treated with respect and dignity in daycare?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 - 0.0
Some of the time	1	0.2	0.0 - 6.7
Most of the time	22	3.8	0.0 – 12.1
Always	532	92.7	80.0 – 100.0
No answer	19	3.3	0.0 – 7.7
Total	574	100	



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

	N	Average (%)	Range (%)
Never	0	0.0	0.0 - 0.0
Some of the time	2	0.3	0.0 - 3.0
Most of the time	39	6.8	0.0 - 25.0
Always	513	89.4	75.0 – 100.0
No answer	20	3.5	0.0 – 8.7
Total	574	100	



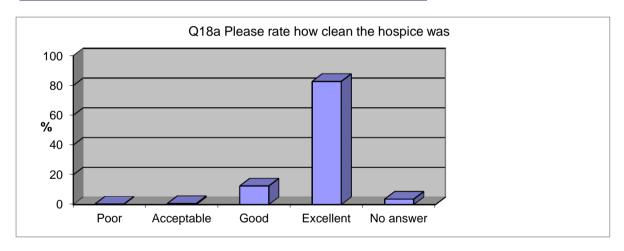
Daycare facilities and services

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 in this survey and in 2010/11 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 how clean the hospice was, the activities available to take part in and the general environment and surroundings. Overall patients were least impressed with the activities available, but there was also considerable variation between hospices. Respondents were invited to make further comments on the facilities and services.

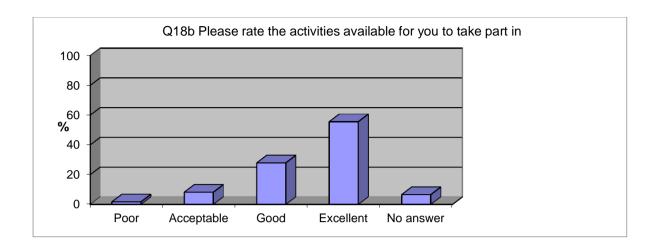
Q18a Please rate how clean the hospice was

, , , , , , , , , , , , , , , , , , ,			
	N	Average (%)	Range (%)
Poor	2	0.3	0.0 - 5.9
Acceptable	4	0.7	0.0 - 6.7
Good	72	12.5	0.0 - 26.9
Excellent	475	82.8	64.5 – 100.0
No answer	21	3.7	0.0 – 13.3
Total	574	100	



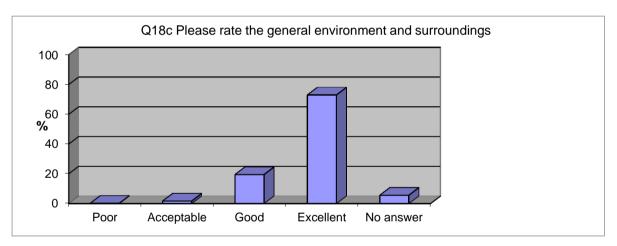
Q18b Please rate the activities available for you to take part in

cross recording desiration desirations for your to take part in			
	N	Average (%)	Range (%)
Poor	10	1.7	0.0 – 25.0
Acceptable	47	8.2	0.0 - 30.8
Good	160	27.9	7.7 – 42.3
Excellent	319	55.6	25.0 – 92.3
No answer	38	6.6	0.0 – 17.6
Total	574	100	



Q18c Please rate the general environment and surroundings

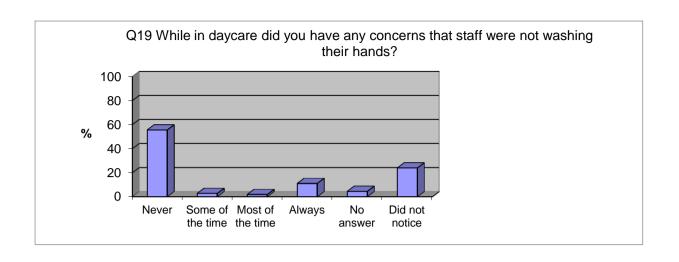
	N	Average (%)	Range (%)
Poor	1	0.2	0.0 - 3.0
Acceptable	10	1.7	0.0 – 12.5
Good	112	19.5	0.0 – 38.5
Excellent	419	73.0	37.5 – 100.0
No answer	32	5.6	0.0 – 12.5
Total	574	100	



The survey asked if patients had concerns about the about staff washing their hands and if they were bothered by noise.

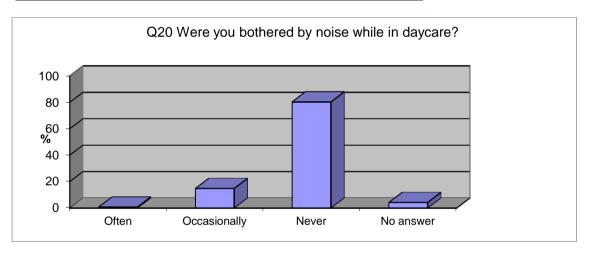
Q19 While in daycare did you have any concerns that staff were not washing their hands?

	N	Average (%)	Range (%)
Never	319	55.6	0.0 - 82.4
Some of the time	16	2.8	0.0 – 8.1
Most of the time	11	1.9	0.0 - 25.0
Always	64	11.1	0.0 – 37.5
No answer	26	4.5	0.0 – 33.3
Did not notice	138	24.0	11.8 – 35.0
Total	574	100	



Q20 Were you bothered by noise while in daycare?

	N	Average (%)	Range (%)
Often	4	0.7	0.0 - 8.3
Occasionally	85	14.8	0.0 – 26.5
Never	461	80.3	60.0 - 100.0
No answer	24	4.2	0.0 - 33.3
Total	574	100	



The survey asked how satisfied patients were with the quality of the catering and the choice of food available.

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

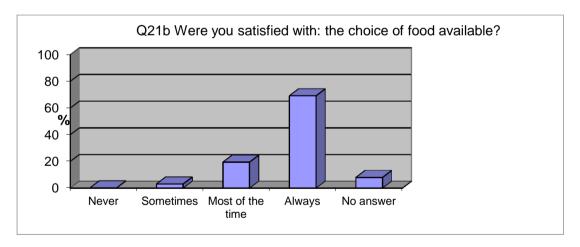
az la violo you outonou vitti. tilo quanty of tilo lood.			
	N	Average (%)	Range (%)
Never	3	0.5	0.0 - 6.7
Sometimes	13	2.3	0.0 – 25.0
Most of the time	105	18.3	0.0 - 40.0
Always	411	71.6	20.0 – 92.3
No answer	42	7.3	0.0 - 33.3
Total	574	100	



There was an improvement in the percentage of patient saying they were always satisfies with the choice of food, from 63% in 2010/11 to 69% this year.

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

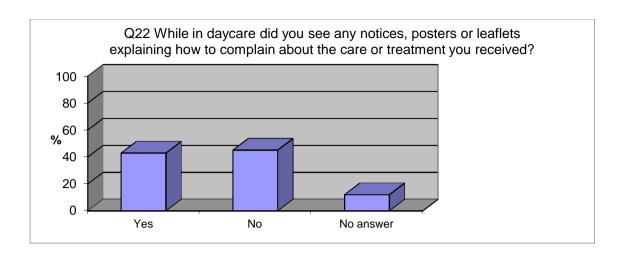
	N	Average (%)	Range (%)
Never	1	0.2	0.0 - 6.7
Sometimes	18	3.1	0.0 – 13.3
Most of the time	112	19.5	2.1 – 42.3
Always	397	69.2	26.7 – 91.5
No answer	46	8.0	0.0 - 20.0
Total	574	100	



Finally, the survey asked if daycare patients had seen notices, posters or leaflets explaining 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	246	42.9	11.8 – 66.7
No	259	45.1	0.0 – 76.5
No answer	69	12.0	0.0 - 33.3
Total	574	100	



Trends in survey findings from 2004/5 to 2012/13

To see how patients' views have changed over time, please refer to Appendix E which compares responses from the questions that have been used throughout this series of hospice surveys. The proportion of people using the **highest** rating only is shown.

Ratings have been remarkably consistent from one survey to the next, and changes over 10 years are quite small. The biggest differences were improvements in the provision of information to daycare patients and reducing daycare patients' levels of anxiety on their first visit, and since 2004/5 fewer daycare patients rating hospice transport as 'excellent'. Daycare patients have also become less satisfied with the activities available, cleanliness, the general hospice environment, and their involvement in planning their care.

These trends give a broad overview of change, as to some extent they will reflect the different mix of hospices each year over the series. Individual hospices will be able to refer to their own reports to make more precise comparisons over time.

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 All Hospices Inpatient Results (18 hospices)

For the first time all hospices are included in average figures irrespective of the number of responses and these results represent the views of all 465 inpatients replying to the survey. This section of the report gives an overview of the aggregate results of all hospices with tables and charts of the findings for each topic covered by the survey. The topics for Inpatients 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 additional questions about visiting arrangements and the explanations received about taking medicines after discharge.

The results, in table form, report the aggregated average patient responses (counts and percentages) for all eighteen hospices. The range of results (minimum and maximum) is also reported, showing the lowest and highest individual hospice percentages for each question. With the inclusion of all hospices irrespective of the number of responses they received, average figures are expected to be much the same as the previous benchmark reporting, but the hospices with small numbers of responses will lead to a wider range of individual results. The aggregated average results displayed in these tables are then reported visually in a bar-chart for each question.

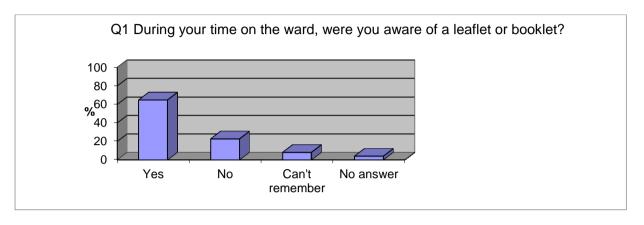
Any notable differences in the results compared to the 2010/11 survey (of -/+5% or more) are reported in the written commentary. However, different groups of hospices taking part in successive surveys make it difficult to interpret how meaningful such comparisons of similarities or differences are. Well-designed surveys should get low proportions giving no answer to individual questions, and whereas it was noted in section 3.2 that this was increasingly happening for daycare patients, it was not the case for inpatients. By and large the number of inpatients not giving a view did not change from 2010/11 to 2012/13, but the proportions not replying rose to 5-6% when asked if inpatients had the opportunity to ask questions of staff and whether they had been able to understand the replies.

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.

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

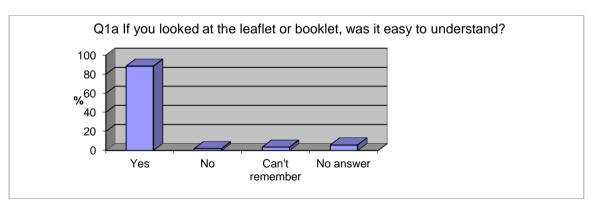
	N	Average (%)	Range (%)
Yes	302	64.9	40.0 – 90.0
No	106	22.8	0.0 - 58.3
Can't remember	38	8.2	0.0 - 30.0
No answer	19	4.1	0.0 – 15.0
Total	465	100	



Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on inpatient services, however there were problems for a handful of people with not finding it easy to understand or finding things that were incorrect. A few inpatients commented on information leaflets - see these in individual hospice reports and summarised in section 5.

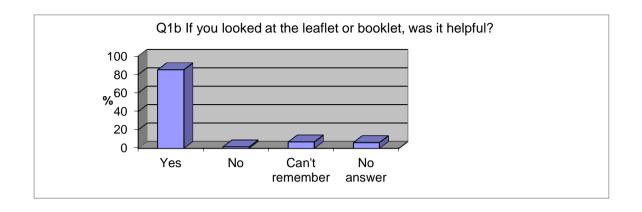
Q1a If you looked at the leaflet or booklet, was it easy to understand?

	N	Average (%)	Range (%)	
Yes	270	88.5	75.0 – 100.0	
No	6	2.0	0.0 – 12.5	
Can't remember	11	3.6	0.0 – 20.0	
No answer	18	5.9	0.0 – 20.0	
Total	305	100		
Did not look at the leaflet or booklet: 16				
Not applicable: 144				



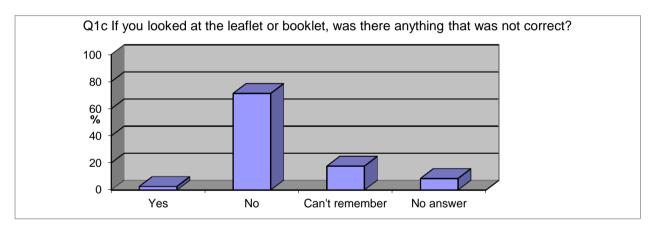
Q1b If you looked at the leaflet or booklet, was it helpful?

	N	Average (%)	Range (%)	
Yes	259	85.2	57.1 – 100.0	
No	5	1.6	0.0 – 16.7	
Can't remember	21	6.9	0.0 - 40.0	
No answer	19	6.3	0.0 - 28.6	
Total	304	100		
Did not look at the leaflet or booklet: 17				
Not applicable: 144				



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

	N	Average (%)	Range (%)	
Yes	8	2.6	0.0 – 28.6	
No	219	71.3	42.9 – 100.0	
Can't remember	54	17.6	0.0 - 40.0	
No answer	26	8.5	0.0 – 23.1	
Total	307	100		
Did not look at the leaflet or booklet: 14				
Not applicable: 144				

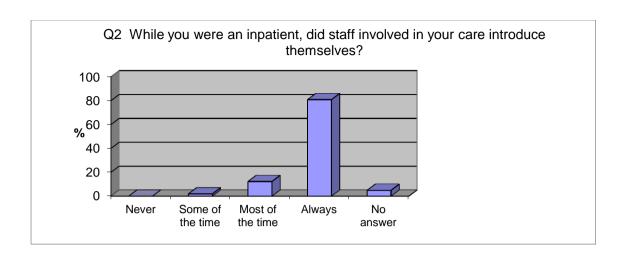


Inpatient Staff: Communication and Care

The survey asked inpatients about the communication and care they had received from staff on the ward.

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

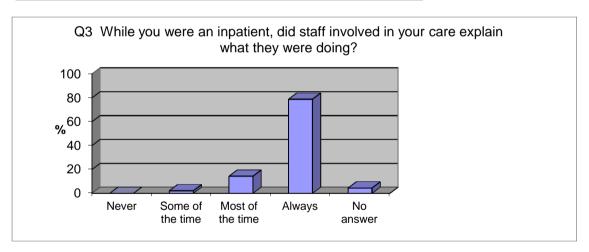
	N	Average (%)	Range (%)
Never	0	0.0	0.0 - 0.0
Some of the time	9	1.9	0.0 – 15.0
Most of the time	57	12.3	0.0 – 22.2
Always	376	80.9	36.4 – 91.4
No answer	23	4.9	0.0 – 59.1
Total	465	100	



As well as staff introducing themselves, patients were asked if the staff gave explanations for what they were doing when involved in their care.

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

	N	Average (%)	Range (%)
Never	0	0.0	0.0 0.0
Some of the time	10	2.2	0.0 – 15.0
Most of the time	67	14.4	7.5 – 30.0
Always	367	78.9	31.8 – 92.0
No answer	21	4.5	0.0 – 59.1
Total	465	100	



Inpatients were also asked whether they had confidence in the staff that were caring for them. An overview of all comments can be found in section 5 of this report.

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

the position of the second sec				
	N	Average (%)	Range (%)	
Never	1	0.2	0.0 - 5.0	
Some of the time	4	0.9	0.0 – 10.0	
Most of the time	63	13.5	0.0 – 32.6	
Always	378	81.3	36.4 – 100.0	
No answer	19	4.1	0.0 – 59.1	
Total	465	100		

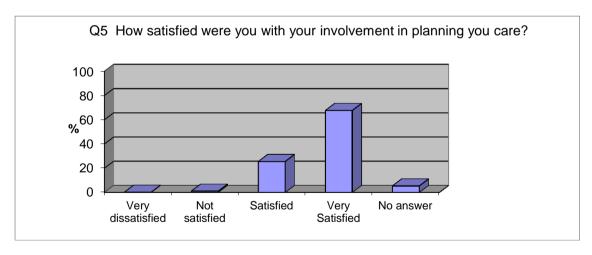


Inpatient user involvement and understanding

Patients were asked how satisfied they had been with their involvement in the planning of their care while on the ward as an inpatient. 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 individual hospice reports and section 5 of this report).

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

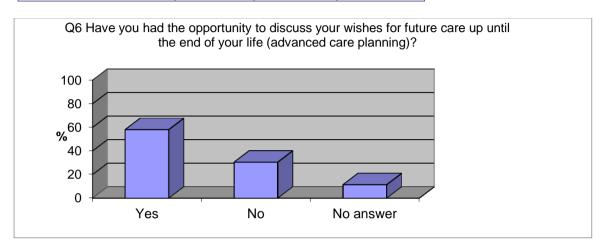
	N	Average (%)	Range (%)
Not at all satisfied	1	0.2	0.0 -2.8
Not satisfied	5	1.1	0.0 - 5.0
Satisfied	119	25.6	40.0 – 6.7
Very Satisfied	315	67.7	22.7 – 86.7
No answer	25	5.4	0.0 – 59.1
Total	465	100	



The next question was about having the opportunity to discuss wishes for future care up until end of life, or advanced care planning. There was a small increase from 55% in the last survey. Comments on this topic were invited.

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

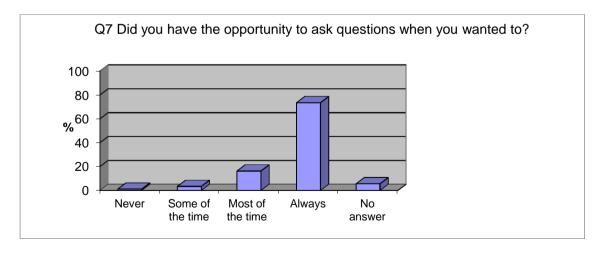
	N	Average (%)	Range (%)
Yes	270	58.1	30.0 – 81.8
No	142	30.5	0.0 - 60.0
No answer	53	11.4	0.0 - 63.6
Total	465	100	



Inpatients were asked if they had had the opportunity to ask questions when they wanted to and if they understood the explanations given to them about their care whilst on the ward. Some respondents suggested ways of making their hospice's explanations clearer.

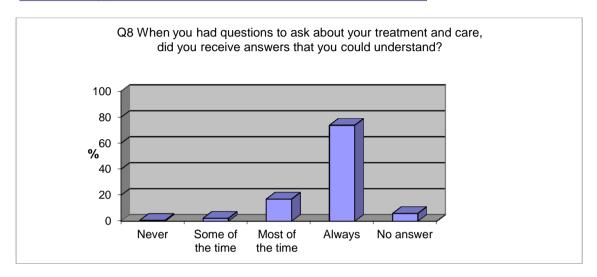
Q7 Did you have the opportunity to ask questions when you wanted to?

	N	Average (%)	Range (%)
Never	5	1.1	0.0 – 5.0
Some of the time	16	3.4	0.0 – 10.0
Most of the time	76	16.3	4.5 – 30.8
Always	342	73.5	31.8 – 88.9
No answer	26	5.6	0.0 – 59.1
Total	465	100	



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

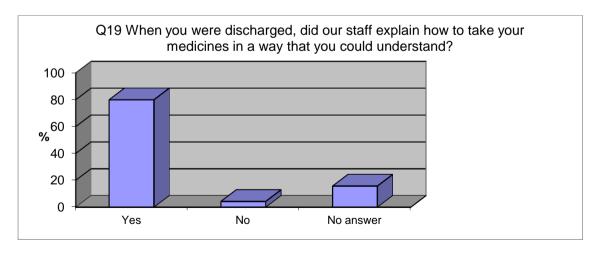
	N	Average (%)	Range (%)
Never	3	0.7	0.0 - 5.6
Some of the time	10	2.3	0.0. – 11.1
Most of the time	74	17.1	0.0 - 38.5
Always	320	73.9	31.8 – 100.0
No answer	26	6.0	0.0 – 10.0
Total	433	100.0	
Did not ask any questions: 32			



There was a question about clarity of the explanations inpatients were given on discharge about how to take medication.

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

·	N	Average (%)	Range (%)
Yes	372	80.0	46.2 – 94.4
No	20	4.3	0.0 – 15.8
No answer	73	15.7	0.0 – 53.8
Total	465	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 question was asked about whether ward staff made an effort to meet religious or spiritual needs. Fewer in 2012/13 said these needs were 'always' met – 59% down from 63% in 2010/11. The high proportion not replying seems to be explained from the comments as 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?

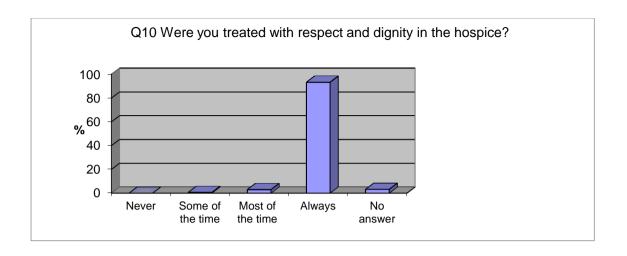
	N	Average (%)	Range (%)
Never	16	3.4	0.0 – 13.3
Some of the time	24	5.2	0.0 - 20.0
Most of the time	53	11.4	0.0 – 24.1
Always	272	58.5	22.7 – 82.5
No answer	100	21.5	0.0 - 63.6
Total	465	100	



The vast majority of inpatients generally felt that staff treated them with respect and dignity and said that their privacy needs were met. Figures were a little higher compared to 2011/11 and the average rating for being treated with respect and dignity is now extremely high.

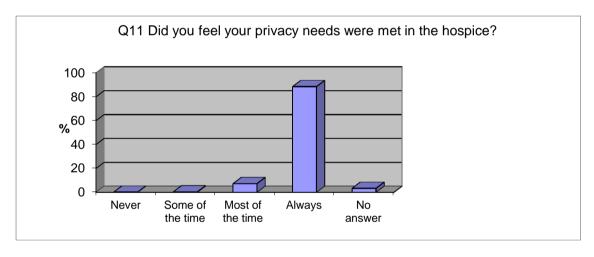
Q10 Were you treated with respect and dignity in the hospice?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 - 0.0
Some of the time	2	0.4	0.0 – 5.0
Most of the time	14	3.0	0.0 – 10.0
Always	434	93.3	80.0 – 100.0
No answer	15	3.2	0.0 – 13.3
Total	465	100	



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

	N	Average (%)	Range (%)
Never	1	0.2	0.0 - 3.4
Some of the time	2	0.4	0.0 – 10.0
Most of the time	34	7.3	0.0 - 25.0
Always	412	88.6	70.0 – 100.0
No answer	16	3.4	0.0 – 13.3
Total	465	100	



Inpatient Facilities and Services

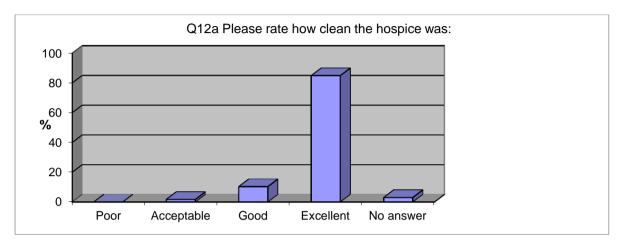
The survey asked a range of questions about how patients rate the facilities and services available to inpatients in their hospice. It asked for views on the general environment, including the cleanliness of the premises, noise and staff hand-washing. Also about the available activities, the quality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

Respondents were invited to make further comments on these facilities and services which can be found in individual hospice reports and section 5 of this report. These clarified why some inpatients did not take part in activities, for example when they were not fit enough.

More inpatients said cleanliness was excellent – 85% compared to 81% in 2010/11.

Q12a Please rate how clean the hospice was:

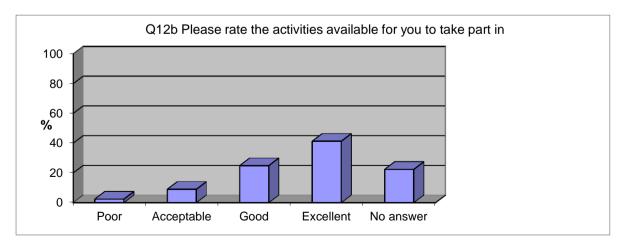
	N	Average (%)	Range (%)
Poor	0	0.0	0.0 - 0.0
Acceptable	8	1.7	0.0 – 15.0
Good	48	10.3	0.0 – 17.2
Excellent	395	84.9	75.9 – 100.0
No answer	14	3.0	0.0 – 10.0
Total	465	100	



There was a large increase in the number of inpatients rating the activities available as 'excellent', from 33% in 2010/11 to 41% in 2012/13, which may be due to the different sample of hospices (as over the same time the % not replying to this question has gone down from 34% to 22%).

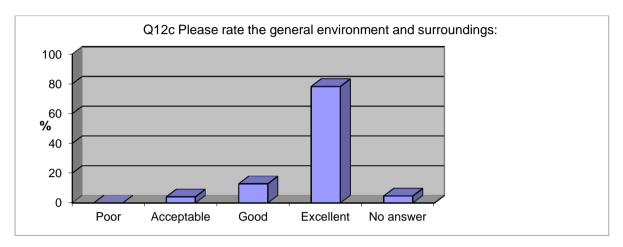
Q12b Please rate the activities available for you to take part in

	N	Average (%)	Range (%)
Poor	11	2.4	0.0 - 20.0
Acceptable	42	9.0	0.0 – 23.1
Good	116	24.9	9.1 – 44.4
Excellent	192	41.3	15.4 – 58.7
No answer	104	22.4	4.3 – 42.5
Total	465	100	



Q12c Please rate the general environment and surroundings:

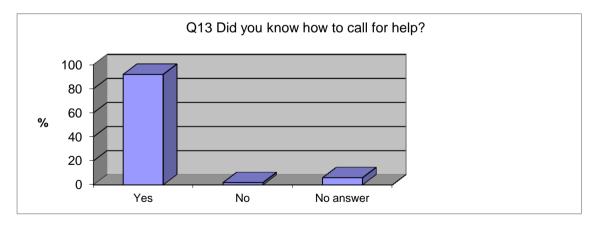
	N	Average (%)	Range (%)
Poor	0	0.0	0.0 - 0.0
Acceptable	19	4.1	0.0 – 15.0
Good	60	12.9	0.0 - 27.3
Excellent	364	78.3	59.14 – 96.0
No answer	22	4.7	0.0 – 10.0
Total	465	100	



Almost all inpatients in the survey knew how to call for help while they were in hospice care, however the small number that did not may need further investigation.

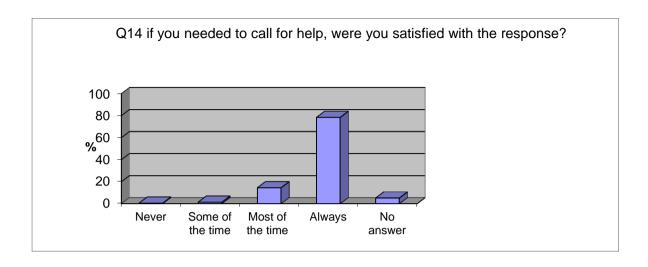
Q13 Did you know how to call for help?

	N	Average (%)	Range (%)
Yes	428	92.0	70.0 – 100.0
No	9	1.9	0.0 – 11.1
No answer	28	6.0	0.0 - 30.0
Total	465	100	



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

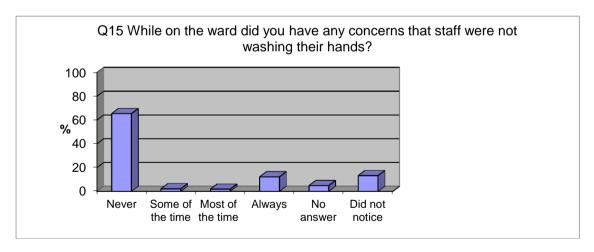
	N	Average (%)	Range (%)
Never	2	0.5	0.0 - 3.6
Some of the time	6	1.4	0.0 – 15.0
Most of the time	61	14.5	0.0 – 27.7
Always	331	78.4	60.0 – 100.0
No answer	22	5.2	0.0 – 20.0
Total	422	100	
Not applicable as did not need to call for help: 43			



The survey asked if patients had concerns about the about staff washing their hands and if they were bothered by noise.

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

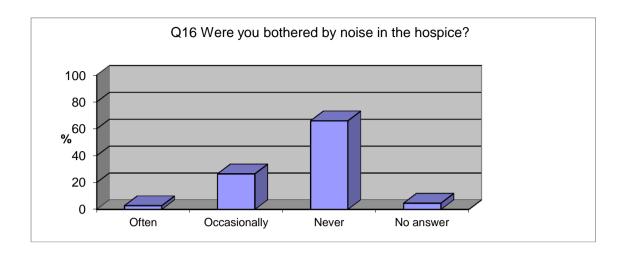
	N	Average (%)	Range (%)
Never	304	65.4	40.0 – 86.4
Some of the time	10	2.2	0.0 – 10.0
Most of the time	9	1.9	0.0 – 10.0
Always	57	12.3	3.4 – 44.4
No answer	23	4.9	0.0 - 20.0
Did not notice	62	13.3	0.0 – 26.1
Total	465	100	



Noise has been more of a problem for inpatients compared to daycare patients, however fewer were bothered in 2012/13 (29% compared to 39% in 2010/11). Patients wrote in comments to elaborate on the noise disturbance, and these appear in individual hospice reports and are summarised in section 5.

Q16 Were you bothered by noise in the hospice?

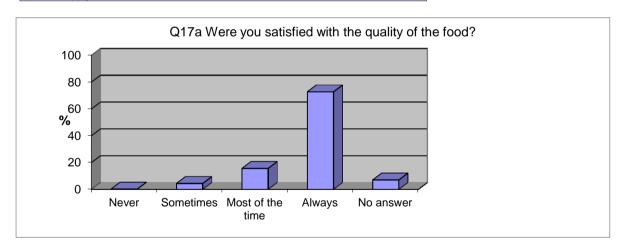
a to vicic you believed by holde in the hospice:			
	N	Average (%)	Range (%)
Often	13	2.8	0.0 – 13.6
Occasionally	123	26.5	5.3 – 45.5
Never	307	66.0	35.0 – 90.0
No answer	22	4.7	0.0 - 20.0
Total	465	100	



Patients were asked how often they were satisfied with the quality of the food, the choice of food available and access to food other than at meal times including at night. The sample in 2012/13 showed greater satisfaction with the quality of food (73% said 'always' compared to 65% in 2010/11).

Q17a Were you satisfied with the quality of the food?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 - 5.3
Sometimes	20	4.4	0.0 – 15.8
Most of the time	71	15.6	0.0 – 34.5
Always	331	72.7	26.3 – 100.0
No answer	32	7.0	0.0 - 26.3
Total	455	100	
Did not apply: 10			



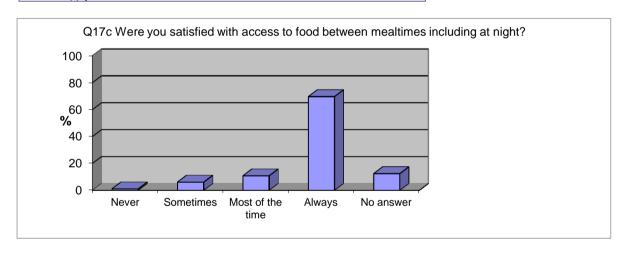
Q17b Were you satisfied with the choice of food available?

	N	Average (%)	Range (%)
Never	2	0.4	0.0 5.6
Sometimes	27	5.9	0.0 – 16.7
Most of the time	80	17.6	4.5 – 32.8
Always	310	68.1	33.3 – 92.9
No answer	36	7.9	0.0 – 27.8
Total	455	100	
Did not apply: 10			



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

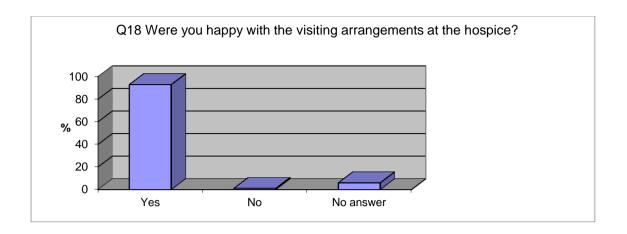
•	N	Average (%)	Range (%)
Never	4	1.1	0.0 – 12.0
Sometimes	23	6.1	0.0 – 21.4
Most of the time	41	10.8	0.0 – 21.1
Always	263	69.6	50.0 – 100.0
No answer	47	12.4	0.0 – 37.5
Total	378	100	
Did not apply: 87			



A question was asked about satisfaction with visiting arrangements, showing a small increase in satisfaction since 89% in 2010/11.

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

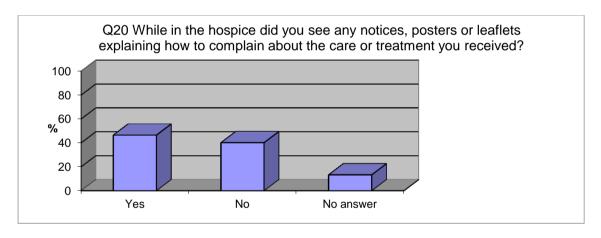
	N	Average (%)	Range (%)
Yes	432	92.9	75.0 – 100.0
No	5	1.1	0.0 – 10.0
No answer	28	6.0	0.0 – 15.0
Total	465	100	



Finally, the survey asked if inpatients had seen notices, posters or leaflets explaining how to make a complaint.

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	216	46.5	10.0 – 70.0
No	187	40.2	15.0 – 70.0
No answer	62	13.3	0.0 - 30.8
Total	465	100	



Trends in survey findings from 2004/5 to 2012/13

To see how patients' views have changed over a longer time frame, please refer to Appendix E which compares responses from the questions that have been used throughout this series of hospice surveys. The proportion of people using the **highest** rating only is shown.

For inpatients there were no major changes, but some reduction in satisfaction regarding confidence in staff, having the opportunity to ask guestions, and the general hospice environment.

Trends from 2004/5 to 2012/13 simply give a broad overview of change, as to some extent they will reflect the different mix of hospices each year taking part. Individual hospices will be able to refer to their own reports to make more precise comparisons over time.

5. Summary of Findings and Comments

Changes in 2012/13

The 2012/13 survey questions and methods were the same as those used in 2010/11. Although fewer hospices took part this time, the number of responses per hospice remained steady, and response rates were slightly up.

All hospices have been included in average figures in sections 3.2 and 4.2 of this report regardless of whether they achieved the recommended number of responses for statistical reliability (which was 40). The verbatim comments are summarised below rather than being analysed in detail.

Satisfaction with hospice services

In 2012/13 patients continued to rate various aspects of hospice care highly, with the highest satisfaction ratings (90% or more) for being treated with respect and dignity, with regard to privacy, and confidence in staff. Inpatients also rated the visiting arrangements very highly. Areas with almost as high levels of satisfaction (80% or more) were quality of information supplied and cleanliness of hospices. Areas with lower levels of satisfaction (60% or less fully satisfied) were for punctuality and comfort of hospice transport, opportunities to discuss end of life wishes, the range of activities available, and awareness of the complaints procedure. Satisfaction levels were broadly similar for daycare patients and inpatients, with the biggest difference being for noise disturbance which was greater for inpatients.

Compared to 2010/11, several of the **daycare** patient ratings showed improvement, most did not change, and a few areas were rated less highly in 2012/13. For daycare patients the areas showing improvement of 4 or more percentage points were: opportunity to discuss advanced care plans, activities available, and choice of food. Areas rated less well in 2012/13 compared to the previous survey were: awareness and helpfulness of hospice information booklets, and staff introducing themselves.

Comparing satisfaction expressed by **inpatients** to the previous survey, improvements were seen across many of the areas surveyed. Topics with better (4 or more percentage point) ratings in 2012/13 were: cleanliness, activities available, disturbance from noise, food quality, and visiting arrangements. A small number of topics were rated similarly to the previous survey, and a small number were rated less highly. The areas with lower ratings were: staff giving explanations, and religious and spiritual needs being met.

Looking at daycare and inpatient services together the 2012/13 survey draws attention to areas where there may be scope for increasing satisfaction, such as the extent to which patients feel involved in care planning and have opportunities for discussing their end of life wishes, and to areas that did less well this year such as how well staff explained what they were doing and the impact of hospice information. However these should be seen in the overall context of hospice services receiving high satisfaction ratings and the 2012/13 results showing improvements in a number of areas.

Variations between hospices in 2012/13

While ratings for individual hospices generally followed the same overall pattern as the aggregated data shown in sections 3.2 and 4.2, there was variation between hospices, and especially so for inpatients, even after allowing for the greater variation to be expected where there are a small number of responses.

Topics where individual hospices' ratings varied for both daycare and inpatients were: awareness of information booklets, being able to understand answers to their questions, having religious and spiritual needs met, available activities, choice of food, and awareness of the complaints procedure. For inpatients alone there was variation also for: levels of satisfaction in individual hospices varied in the following: staff introducing themselves, staff

explaining what they were doing, confidence in staff, involvement in care planning, opportunities to discuss end of life wishes, privacy, hospice environment, knowing how to call for help, the response to calling for help, staff hand washing, being disturbed by noise and access to food. While survey results are overall extremely encouraging and hospice services continue to be rated very highly, this variation can be used by individual hospices to highlight a few specific areas that they may wish to investigate.

Overview of the comments

Comments from patients in the survey were overwhelmingly positive as has been the case in previous years, and sections 3.1 and 4.1 of individual hospice reports contain all the comments made by their patients.

The purpose of inviting comments was to identify where there were problems and for patients to elaborate their answers thereby helping hospices to improve services. Therefore, rather than reiterating all the praise and appreciation from patients about their experiences in hospice, which came through loud and clear, comments that hospices can act upon are summarised here.

Daycare patients made 1197 comments, which included enormous amounts of praise for staff and the services received, for example, in dealing with patients' anxiety on their first visit, and there were hardly any suggestions as to how respect/dignity, privacy, hand washing, or the complaints procedure could be improved. Nevertheless about one in seven of the comments (243) provide patient views that can help hospices improve services. Most numerous of these were about end of life planning and religious and spiritual needs, even after allowing for the high numbers that felt they did not want to discuss end of life plans and did not have religious or spiritual needs. Although many were not ready for it, quite a few said they would have liked the opportunity to discuss their end of life wishes in more depth. Quite a number also said that there had been no discussion about their religious and spiritual needs.

Other areas attracting comments from daycare patients were transport and other hospice facilities. Some would have liked to have known more about what to expect during their stay from information booklets. Transport received some criticisms about pick-up times, drivers, and comfort and state of vehicles. Background noise levels were a problem for some when they had hearing aids and when it affected group sessions, and noise from staff, patients and workmen was cited as a nuisance. A number of daycare patients gave the reason they did not like the food, which included the way it was cooked and seasoned, and made requests that vegetarians/diabetics/dairy-free and people with other dietary requirements were better catered for. With regard to activities, some daycare patients wanted more trips out, art, physical exercises, etc, and some felt the hospice environment was not always suitable in terms of access and the space it provided.

Inpatients made 1127 comments, the majority of which were full of praise for hospices, but just over a fifth (241) were about a specific issue or making suggestions for improvements. The most numerous comments in this category related to patients being disturbed by noise, although patients often acknowledged that some noise could not be helped. The next most numerous comments were about the available activities, and general comments at the end of the questionnaire which tended to re-iterate comments made earlier in the questionnaire. Inpatients' comments on some questions helped to clarify a negative response when services were not particularly relevant to or needed by all patients, for example, some did not want to discuss advance care plans, did not want religious or spiritual support, did not take part in activities, did not find noise levels disturbing, were not discharged with medication, and did not want to make any complaints.

Inpatients' suggestions ranged from wanting better communication, more appropriate activities, more facilities in rooms and a few suggested making more of fund-raising opportunities. There were some comments by patients who were looking for improvements in information and communication, for example translations for non-English speakers, more information and involvement in their care, and better coordination between staff providing their care. A few commented that they would have liked more opportunity to discuss end of life wishes, but there were more comments from people who did not or were not ready. Some were dissatisfied with the speed of response when calling for help, and others cited examples of a lack of privacy. Available activities and facilities attracted comments, with some patients saying there weren't sufficient activities for inpatients, there should be better advertising of activities, or trips out. Some asked for better access to food, such as a snack trolley or tea-making

facilities in their rooms, others wanted more space or seating for their visitors. Inpatients' comments on noise referred to a very wide range of disturbance from sources including other patients, visitors, TV/music, staff areas, trolleys, cleaning and building works, and especially when these occurred at otherwise quiet times such as early morning, evening or night-time.

Trends over time

Although question wording and response options have changed over time, with new questions being added and others being dropped, there are some parts of the survey that have not changed. A comparison of the common questions has been given from the start of the series of surveys in 2004/5 (Appendix E), showing the percentages of patients using the highest rating scores.

Ratings have been remarkably consistent from one survey to the next, and changes over 10 years are quite small. The biggest differences were improvements in the provision of information to daycare patients and reducing daycare patients' levels of anxiety on their first visit, and since 2004/5 fewer daycare patients rating hospice transport as 'excellent'. Daycare patients have also become less satisfied with the activities available, cleanliness, the general hospice environment, and their involvement in planning their care. For inpatients there were no major changes, but some reduction in satisfaction regarding confidence in staff, having the opportunity to ask questions, and the general hospice environment.

Only a few of these trends are large and all should be interpreted with caution, as they represent responses from different combinations of hospices taking part each year and they appear to be affected by small changes in the response options patients could choose. In addition trend data only gives a partial view as it does not include more recently added or improved questions.

Issues for hospices

Although high levels of satisfaction have been expressed throughout the hospice patient survey, some may wish to focus on areas where ratings have fallen or where there is scope for more improvement. For example, awareness of hospice information booklets has improved but many patients still do not see hospice information and there is considerable variation between hospices. Likewise a large proportion of patients do not see information about how to make a complaint.

Some aspects of staff behaviour and communication, especially for inpatients, were unevenly rated or received slightly poorer ratings in 2012/13 compared to 2010/11, specifically staff introducing themselves, staff saying what they were doing and answering questions in a way patients could understand. Two topics continued to be difficult for both hospices and patients, and these were creating and making use of opportunities for end of life discussions and making appropriate provisions for patients' religious and spiritual needs. Both of these are of course highly personal issues for an individual patient.

Satisfaction with the range of available activities continued to be an issue for some patients in 2012/13, as was the choice of food. Also quite a large proportion of patients were disturbed by noise while in the hospice, and over the survey series there has been some reduction in satisfaction with transport, around the aspects of punctuality and comfort.

6. Considerations for the Future

This survey may serve as the last in its current form, given the many additional opportunities that are beginning to emerge to engage users of hospices in discussion regarding their experience of care and how they would suggest it is improved. This survey has served as a valuable starting point in listening to the views of patients who receive inpatient or day care from hospices and we are most grateful to the many hospices and their patients that have taken part in it the last 10 years and have supported its development.

Opportunities exist to develop it further including, for example, implementation of real time reporting; to find ways in which the views of users can be fed back to those responsible for delivering care within a much shorter time frame. When this is within days or weeks, it may allow improvements that could even benefit those who have raised the concern or identified the opportunity for change. New technology exists to support the capture, transfer and description of data within timescales previously unimaginable.

There are also real opportunities to engage users in a more iterative dialogue about how services are best shaped in the future to reflect their needs and preferences. This process of co-design of services is of growing interest to hospices, the communities they serve and their local commissioners. There is evidence from hospices who have begun to get to grips with this process that it is immensely rewarding for all involved.

Any process fit for the future must be able to collect data from a broad range of users of hospice care beyond patients, including families and family carers. It must also review the experience of people who are being cared for at home and in other community settings, as well as those in institutional contexts. Wherever possible it will provide a locality wide perspective, so that commissioners, planners, hospices and anyone else with a population wide responsibility to ensure appropriate palliative and end of life care services can identify gaps in provision or areas of poor quality that must be improved .

So, this survey has served as a valuable step along a journey of increasing user involvement in assessment and improvement in the quality of care. It has made valuable strides in establishing a rigorous approach in identifying important questions to ask of users and analysing and reporting on what they say. It has offered helpful insights into the value of benchmarking findings between hospices and has confirmed the importance of building a sector wide approach to such developments. Our sincere thanks to the University of Kent and the Survey Group for their significant role in achieving this.

To know more about developments on the part of Help the Hospices to capture and build on user views at local and national levels contact clinical@helpthehospices.org.uk

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

APPENDIX A

DAYCARE QUESTIONNAIRE 2012/2013

Your hospice logo

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					
	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					
	C. Was there anything in the leaflet or booklet that was not correct? No					

		y suggestions for other information that should he leaflet or booklet?
2.		s at the beginning of your first visit to day care?
	Very anxious Anxious Not at all anxious	
3.		s at the end of your first visit to day care? x closest to your view.)
	Very anxious Anxious Not at all anxious	
4.	Was there anything anxious?	more we could have done to make you feel less
5.	Did you use transpo No Yes	ort organised by the hospice? ☐ Please go to question 7. ☐ 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 time	picked up on							
Comfort of the jour	ney							
Safety of the journe	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 □	Some of the time	Mos	t of the time	Al	ways			
	nvolved in your c							
Never □	Some of the time □	Mos	it of the time	Al	ways □			
9. Did you have confidence in the staff who were caring for you?								
Never	Some of the time	Mos	t of the time	Al	ways			
Do you have any further comments?								

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

Not at all satisfi	ed Not satis	fied S	atisfied	Very satisfied □					
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	Some of the time	Most of the time	Always	Did not ask any questions					
13. When you had questions to ask about your treatment and care in day care, did you receive answers that you could understand?									
Never	Some of the time	Most of the time	Always	Did not ask any questions					
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	Some of the time	Most of the time	Always □					
Do you have any further comments?								
15. Did you feel day-care staff made an effort to meet your religious or spiritual needs?								
Never	Some of the time	Most of the time	Always □					
Do you have any fu	urther comments?							
16. Were you trea	ated with respect a	nd dignity in day ca	ire?					
Never □	Some of the time	Most of the time	Always					
Do you have any further comments?								
17. Did you feel your privacy needs were met in day care?								
Never	Some of the time	Most of the time	Always □					
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 hospic	ce						
Activities availa part in	ke							
The general ensurroundings	vironment and							
Do you have ar	ny further comme	ents?						
	ay care, did yo their hands?	u have any co	oncerns that s	staff we	re not			
Never	Some of the time	Most of the time	Always		Did not notice			
Do you have ar	ny further comme	ents?						
20. Were you bothered by noise while in day care?								
Often Occasionally Never								
If you were, it w	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 y	ou have any further com	ments?							
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 y	ou have any further com	ments?							
23.	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?									

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.



APPENDIX B

INPATIENT QUESTIONNAIRE 2012/2013

Your hospice logo

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 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						

/hil	le you were in	[enter the name of	f the hospice here]:	
	Did the staff	involved in your c	are introduce them	selves?
	Never	Some of the time	Most of the time	Always
	ш	<u> </u>		
.	Did the staff	involved in your c	are explain what the	ev were doing?
<u>, </u>	Never	Some of the time	Most of the time	Always
١.	Did you have	e confidence in the	staff who were car	ing for you?
	Never	Some of the time	Most of the time	Always
Оо у	ou have any fu	urther comments?		
		d were you with ho	w involved you we	re in planning
5.	VALIF CORD /			
	your care? Not at all	Not satisfied	Satisfied	Very satisfied
	-	Not satisfied	Satisfied	Very satisfied

6.		ı had the oppor I the end of you □ □	_		•			
Do you have any further comments?								
7.	Did you h	nave the opport	unity to	o ask qu	estions wh	nen yo	ou wanted	
	Never	Some of the	e time	Most o	f the time □		Always	
8.	_	u had questions ive answers tha		_		nent a	nd care, did	
	Never	Some of the time		of the ne	Always	6	Did not ask any questions	
Do you have any further comments?								
9. Did you feel ward staff made an effort to meet your religious or spiritual needs?								
	Never	Some of the	e time	Most o	f the time □		Always	
Do	Do you have any further comments?							

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

	Some of the time	Mos	st of the time	Al	ways			
Do you have any fu	urther comments?							
11. Did you f	eel your privacy ne	eds v	vere met in th	e hospi	ce?			
Never	Some of the time	Mos	st of the time	Al	ways			
Do you have any fu	irtner comments?							
12 Places re	to the following by	4iakir	ag the engree	rioto bo				
12. Please ra	te the following by	tickir	ng the approp	riate bo	x.			
12. Please ra		tickir Poor	ng the approp	riate bo	x. Excellent			
12. Please ra				_				
	nd the hospice			_				
How clean you four	nd the hospice for you to take			_				
How clean you four Activities available part in The general enviro	nd the hospice for you to take nment and			_				
How clean you four Activities available part in The general enviro surroundings	nd the hospice for you to take nment and			_				

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

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

	Never	Sometimes	Most of the time	Always	Did not apply to me		
The quality of the fo	od						
The choice of food available							
Access to food between mealtimes, including during the night							
Do you have any fu	ther comme	ents?					
18. Were you happy with the visiting arrangements at the hospice? No							
19. When you were discharged, did our staff explain how to take your medicines in a way that you could understand?							
No Voc							
Yes	Ш						
Do you have any fu	ther comme	ents?					

INPATIENT QUESTIONNAIRE Hospice Code

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							
Do y	ou 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

Response Statistics – across all Help the Hospices Patient Surveys

		2004/05	2006/07	2008/09	2010/11	2012/13
No. of hospices	All hospices	53	53	52	39	20
participating	All Daycare	50	49	46	37	19
	All Inpatient	46	48	46	35	18
	Both services	43	44	40	33	17
	Just Daycare	7	5	6	4	2
	Just Inpatient	3	4	6	2	1
Returned	Daycare	1398	1352	1259	1150	574
questionnaires	Inpatient	926	1052	963	834	465
	Total	2324	2404	2222	1984	1039
Average no.	Daycare	28	28	27	31	30
returns per	, , , ,	(3-59)	(8-53)	(4-60)	(2-57)	(3-62)
hospice	Inpatient	20	22	21	24	26
(min-max)	-	(4-59)	(2-58)	(2-56)	(6-46)	(9-58)
Response rate	Daycare	-	61% (from 28	62% (from 25	62% (from 35	64% (from 19
			hospices)	hospices)	hospices)	hospices)
	Inpatient	-	49%	41%	45%	50%*
			(from 29	(from 25	(from 33	(from 17
			hospices)	hospices)	hospices)	hospices)
Number of	Daycare	13	10	9	13	7
hospices with 40+ returns	Inpatient	5	9	4	4	4
Data collection period		7 months	8 months	8 months	8 months	7 months

^{*} In 2012/13 the average inpatient response rate excludes hospice ID 106, where data on number of surveys handed out was incomplete

APPENDIX D

Help the Hospices Patient Survey 2012/13 Final number of returned questionnaires – August 2013

Hospice Name	Town/city	Daycare services	Inpatient services	Total
St Andrew's Hospice	Grimsby	33	19	52
St Ann's Hospice	Manchester	47	29	76
St Richards Hospice	Worcester	62	N/A	62
Wigan and Leigh Hospice	Wigan	17	15	32
St Luke's Hospice Harrow	Harrow	26	25	51
Hospice in the Weald	Tunbridge Wells	46	48	94
Pilgrims Hospice	Ashford	49	36	85
Southern Area Hospice Services	Newry	17	40	57
St Luke's Hospice Sheffield	Sheffield	47	22	69
Highland Hospice	Inverness	13	18	31
EllenorLions Hospices	Northfleet	46	15	61
St Luke's Hospice Plymouth	Plymouth	26	22	48
Weldmar Hospice Care Trust	Dorchester	40	20	60
St Joseph's Hospice	London	8	58	66
Mary Stevens Hospice	Stourbridge	37	9	46
Pembridge Palliative Care Centre	London	3	20	23
Hospice Isle of Man	Isle of Man	12	10	22
Norfolk Hospice	King's Lynn	15	N/A	15
Helen & Douglas House	Oxford	N/A	46	46
St Teresa's Hospice	Darlington	30	13	43
Total returned		574	465	1039

APPENDIX E Trends in average results from 2004/5 to 2012/13

Responses to questions that have been used throughout this series of patient surveys are given in the table below. It simply shows the percentage of patients using the highest satisfaction rating, and indicates where minor changes were made to some of the response options in 20010/11 (when a 1-5 point scale was replaced with three or four labelled options). All hospices that took part are included in the table, but it should be noted that the number and mix of hospices was different each year.

Survey	Question number in 2012/13	Question	% in 2004/5	% in 2006/7	% in 2008/9	% in 2010/11	% in 2012/13	Response labels before 2010/11	Current response labels
Daycare	1	During your time in day care here, were you aware of the information leaflet or booklet?	53.3	63.4	59.8	67.7	66.2	yes	yes
Daycare	2	Did you feel anxious at the beginning of your first visit to daycare?	12.5	14.6	11.7	15.5	14.6	5=extremely anxious	very anxious (3pt scale)
Daycare	3	Did you feel anxious at the end of your first visit to daycare?	2.6	2.4	3.0	0.9	0.5	5=extremely anxious	very anxious (3pt scale)
Daycare	6a	If you used hospice transport, please rate whether you were picked up on time	74.0	73.2	73.1	58.4	59.8	5=excellent	excellent (4pt scale)
Daycare	6b	If you used hospice transport, please rate comfort of the journey	73.3	72.0	72.3	60.5	57.6	5=excellent	excellent (4pt scale)
Daycare	6c	If you used hospice transport, please rate safety of the journey	79.5	80.4	81.9	67.9	70.3	5=excellent	excellent (4pt scale)
Daycare	7	Did the staff involved in your care introduce themselves?	80.3	83.9	82.2	83.6	78.7	always	always
Daycare	8	Did the staff involved in your care explain what they were doing?	72.8	74.7	73.7	77.4	75.1	always	always
Daycare	9	Did you have confidence in the staff who were caring for you?	90.2	92.2	90.4	89.7	89.0	always	always
Daycare	10	How satisfied were you with how involved you were in planning your care?	68.3	70.0	59.9	57.3	61.8	very satisfied	very satisfied

Daycare	12	Did you have the opportunity to ask questions when you wanted to?	76.4	73.4	75.2	71.3	72.6	always	always
Daycare	18a	Please rate how clean you found the hospice	87.7	85.9	88.6	80.4	82.8	5=excellent	excellent (4pt scale)
Daycare	18b	Please rate activities available for you to take part in	61.4	59.2	58.4	52.6	55.6	5=excellent	excellent (4pt scale)
Daycare	18c	Please rate the general environment and surroundings	85.6	83.4	82.6	71.2	73.0	5=excellent	excellent (4pt scale)
Daycare	21a	Were you satisfied with the quality of the food	75.1	71.4	72.7	69.4	71.6	5=excellent	excellent (4pt scale)
Inpatient	1	During your time here, were you aware of the information leaflet or booklet?	62.2	67.5	65.9	65.6	64.9	yes	yes
Inpatient	2	Did the staff involved in your care introduce themselves?	77.0	78.2	78.0	77.3	80.9	always	always
Inpatient	3	Did the staff involved in your care explain what they were doing?	75.3	78.2	74.4	77.8	78.9	always	always
Inpatient	4	Did you have confidence in the staff who were caring for you?	87.3	84.3	86.0	84.5	81.3	always	always
Inpatient	5	How satisfied were you with how involved you were in planning your care?	71.2	70.9	66.8	68.0	67.7	very satisfied	very satisfied
Inpatient	7	Did you have the opportunity to ask questions when you wanted to?	78.3	79.6	76.4	73.6	73.5	always	always
Inpatient	12a	Please rate how clean you found the hospice	82.9	76.4	82.6	81.2	84.9	5=excellent	excellent (4pt scale)
Inpatient	12c	Please rate the general environment and surroundings	83.9	81.3	84.0	78.8	78.3	5=excellent	excellent (4pt scale)
Inpatient	17a	Were you satisfied with the quality of the food	70.1	66.8	70.5	65.1	71.2	5=excellent	excellent (4pt scale)
Inpatient	17c	Were you satisfied with access to food between mealtimes, including during the night	59.0	55.5	60.1	66.5	56.6	5=excellent	excellent (4pt scale)