University of Glasgow Settlement

St Margaret of Scotland Hospice

Open to All in Need of Care

Audit Report

Audit of Living and Dying Well based on Patient Experience of Non-Specialist Palliative Care

September 2012

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Executive Summary:

Background:

Published in 2008, Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland (L&DW) aims to provide fair access to good quality palliative care for all who require it. Narratives from patients, carers and healthcare staff in St Margaret of Scotland Hospice (SMOSH) suggested that L&DW had not yet been fully and successfully implemented. Consequently, the need for an audit was identified. .

Aim:

To assess patient perceptions on whether specific action points (2, 4, 10, 16) taken from L&DW are being implemented consistently and for the majority of patients with palliative care needs.

Methods:

This was a retrospective audit using structured questionnaires which enquired about the patients' perception of their care prior to receiving any Hospice services. Each question was designed to assess one action point from the guidelines. The sample consisted of 30 patients attending the Edwina Bradley Day Hospice or receiving services from the Community Specialist Palliative Care Team of SMOSH. Data analysis was performed using SPSS to calculate frequencies and conduct cross-tabulations for the sample split by gender, age and diagnosis

Results:

Positive findings included the adequate assessment of physical, social and environmental needs, quick provision of needed adaptations or equipment and sufficient provision of patient-centred care for the majority of patients. Conversely, assessment of emotional, spiritual and financial needs and provision of information regarding ACP, Thinking-Ahead and e-PCS was poor for the majority of patients. Answers regarding certain aspects of care provision differed noticeably between groups when the sample was split based on age and diagnosis but statistical significance of these differences was impossible to determine due to the small number of participants.

Conclusion:

The findings demonstrate that patient experience of the delivery and quality of non-specialist palliative care remains variable. This suggests L&DW has not yet achieved its aim of improving palliative care for all who require it. Further work, with a larger sample size, is necessary to improve the holistic assessment of patients, the communication between healthcare professionals and the provision of information for patients.

Introduction:

Background:

Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland was introduced by the Scottish government in October 2008 with the aim of enabling "all NHS Boards to plan and develop services which will embed a cohesive and equitable approach to the delivery of palliative and end of life care for patients and families living with and dying from any advanced, progressive or incurable condition across all care settings in Scotland"[1]. The strategies of the Action Plan were condensed into Action Points which all health boards were asked to implement for their populations.

Despite an earlier positive evaluation of this action plan in January 2011,[2] narratives of patients and families accessing services from St Margaret of Scotland Hospice suggested that patient experience may not reflect successful implementation of these guidelines. Patients often commented on the impact of poor communication, assessment, and availability of quality or consistent care at home. Additionally, patients commented on the impact of poor carer support via availability of respite care, availability of equipment, and quality of information shared with the out of hours service or emergency departments. Professionals involved in the care of these patients often highlighted the existence of confusion across the different care settings regarding each setting's roles and responsibilities towards the patients. Additionally, professionals often complained of a lack of collaboration, proactive anticipation and effective care planning. The Community Specialist Palliative Care Complex Case Review Meeting was the forum where the Hospice Multidisciplinary Team would hear of such issues. Throughout these meetings, it was evident that the implementation of Living and Dying Well may not have yet improved care for all those it was designed for.

Prior to the audit commencing, three focus groups were conducted with patients of St Margaret of Scotland Edwina Bradley Day Hospice to elicit the legitimacy of these growing concerns. The patients' responses made clear that there appear to be issues surrounding the communication between healthcare staff and patients, particularly when it comes to discussing patient referral to specialist palliative care. A second, and perhaps more concerning, theme to arise from the focus groups was the lack of information offered to patients – often specifically relating to their diagnosis. Both the communication and sharing of information issues also appeared to negatively impact upon patient awareness of documents such as the Anticipatory Care Plan (ACP) and the Electronic Palliative Care Summary (e-PCS). In addition, there were also variations in the perceived levels of assessment and support that patients received with respect to their holistic palliative needs. Indeed, many patients noted that most of their emotional and financial support

came from their families. The relationship between the key themes arising from patient experience and the corresponding action points within Living and Dying Well became the basis upon which an audit was devised in order to assess the implementation of certain Action Points in the palliative care guidelines.

The aforementioned experience has indicated that the action points in question may not be fully and consistently implemented in clinical practice. Thus, an audit was needed to assess compliance with Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland hoping that this could lead to the development of recommendations for clinical practice, service design and operational planning. Given the main themes identified from the focus groups, the audit team decided to focus the present audit on Action Points number 2, 4, 10 and 16 which recommended the following:

Action Point 2: "NHS Boards, through palliative care networks and CHPs, should ensure that patients identified with palliative and end of life care needs are appropriately assessed and reviewed in all care settings using recognized tools currently available."[1 (p.10)]

Action Point 4: "CHPs [Community Health Partnerships], palliative care networks, older peoples services and LTC [Long Term Conditions] teams in each NHS board area should collaborate to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person-centred and responsive to the needs of the diversity of the population at appropriate stages of the patient journey."[1(p.15)]

Action Point 10: "NHS Boards should ensure that rapid access is available to appropriate equipment required for the care of those wishing to die at home from any advanced progressive condition."[1(p.16)]

Action Point 16: "NHS Boards should ensure that safe and effective processes, electronic or otherwise, are in place 24/7 to enable the transfer, to all relevant professionals and across sectoral and organizational boundaries of patient information as identified in the e-PCS regarding any patient identified as having palliative and end of life care needs and who gives consent."[1(p.19)]

Aim of Audit:

To assess patient perceptions on whether specific action points (2, 4, 10, 16) taken from Living and Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland are being implemented consistently for patients with palliative care needs.

Objectives:

1. To assess whether patients with palliative care needs were identified in a timely manner.
2. To determine whether these patients' physical, psychological, social, environmental, spiritual and financial needs were comprehensively assessed throughout their care.
3. To assess whether appropriate support was provided to meet the patient's palliative needs.
4. To assess whether patients had rapid access to the required adaptations and equipment.
4. To determine whether the majority of the patients were offered the opportunity to create an anticipatory care plan (ACP).
5. To determine whether patients were offered the opportunity to make their data and wishes accessible via the electronic palliative care summary (e-PCS).

Methodology:

Audit type:

Retrospective audit using patient questionnaires.

Data source:

Survey of patients in West Dunbartonshire using structured questionnaires.

Quality Control:

The protocol and all documents related to this audit were reviewed by all the audit team members and approved by the Hospice Chief Executive. This audit was reviewed by the Hospice Clinical Governance Team.

Questionnaires:

Three focus groups, comprising a total of 11 patients attending the Edwina Bradley Day Hospice, were conducted in the Hospice in June 2012. Participant answers were transcribed and the main themes were identified by three members of the project team independently and then jointly agreed upon. These themes were used to construct a structured patient Questionnaire. (see **Appendix 1**, page 61) The Questionnaire enquired about patient experience before their referral to St Margaret of Scotland Hospice. Questionnaires were checked by the audit team and one independent Hospice staff member to make sure the questions reflected the action points being assessed. The action point that each question addressed was noted next to the question on the Questionnaire. Questionnaires were also checked for appropriateness of level of language by an NHS Quality Coordinator independent to the Hospice. Additionally, Questionnaires were checked for test-retest reliability by asking six participants to complete the Questionnaire twice on the same day. It was agreed that a percentage agreement of 90% would be sufficient to establish that test-retest reliability was sufficiently high. During testing, the percentage agreement was found to be 82.5%. Following that, changes were made to the Questionnaire based on patient feedback. For example, one question which the patients found difficult to understand was removed. In addition, in the initial Questionnaire, answer options for some of the questions were offered in the form of a Likert scale (strongly agree, agree, disagree, and strongly disagree) but patients seemed to find that confusing and it appeared to have an adverse effect on the test-retest reliability. Thus, the

Likert scale was replaced with simpler “yes”, “no” and “I am not sure” options for the relevant questions. Finally, the answer options available for question 6a were altered to better reflect circumstances described by patients. The final version (see **Appendix 1**, page 61) was re-tested with six different patients, giving a percentage agreement of 85%. The audit team decided that since all changes suggested by patient feedback had been implemented and given the characteristics of our sample in terms of age and health condition as well as the recall-based nature of this audit, it was appropriate to proceed with the Questionnaire despite the test-retest reliability not reaching the 90% agreement initially aimed for.

Eligibility Criteria:

Inclusion criteria:

1. Patients attending the Edwina Bradley Day Hospice or receiving services from the Community Specialist Palliative Care Team of St Margaret of Scotland Hospice

2. Patients must have first attended the Edwina Bradley Day Hospice or had their first visit from the Community Specialist Palliative Care Team before August 16th 2012

3. Patients meeting the criteria below as relevant to their diagnosis, or, (should none of the information be available in the patient’s file) patients were first added to the palliative care register after January 2009.

    a. **Patients with malignant disease**:

    (Based on information that the Hospice clinical team responsible for their care will retrieve from the patients’ case notes)

    - Initial diagnosis of a malignant, life-limiting illness after January 2009

    or

    - Most recent recurrence diagnosed after January 2009

b. **Patients with chronic heart failure (CHF)**:

(Based on information that the Hospice clinical team responsible for their care will retrieve from the patients' case notes)

- Patient first met the criteria for **Class III or IV heart failure**, based on the New York Heart Association classification[3], after January 2009
- If the classification is not specifically noted in patient record:
  - If it is implied by the record that the patient has had "marked limitation of physical activity (comfortable at rest but less than ordinary activity results in symptoms)", then this would be considered as an indication of Class III heart failure
  - If it is implied by the record that the patient has been unable "to carry out any physical activity without discomfort (symptoms of heart failure are present even at rest with increased discomfort with any physical activity)" would be considered as an indication of Class IV heart failure.

c. **Patients with chronic obstructive pulmonary disease (COPD)**:

(Based on information that the Hospice clinical team responsible for their care will retrieve from the patients' case notes)

- Patient first met the criteria for **Class III or IV COPD**, based on the GOLD COPD guideline classification[4], after January 2009
- If the classification is not specifically noted in patient record:
  - If there is record of a measurement of $30\% \leq FEV_1 < 50\%$ of predicted, or it is implied that the patient had "breathlessness on minimal exertion e.g. dressing", then this would be considered as an indication of Class III COPD
  - If there is record of a measurement of $FEV_1 < 30\%$ of predicted (or $FEV_1 < 50\%$ of predicted accompanied by respiratory failure), or it is implied that the patient had "breathlessness at rest" then this would be considered as an indication of Class IV COPD.

d. **<u>Patients with motor neurone disease (MND)</u>**:

(Based on information that the Hospice clinical team responsible for their care will retrieve from the patients' case notes)

- Patient first met the criteria for **<u>at least</u> Stage 3 Advanced Motor Symptoms**, based on the MND Scotland Integrated Care Pathway[5], after January 2009. If the classification is not specifically noted in patient record, then if one of the following is implied by the record, it should be considered as an indication of Stage 3:
    - Muscle wasting and weight loss
    - Patient requires caregiver assistance for some ADLs
    - Most activities are tiring, requiring frequent rest breaks
    - Increased use of assistive devices to compensate for loss of ability

or

- Patient first met the criteria for **<u>at least</u> Stage 2 Diet Texture Modifications Required**, based on the MND Scotland Integrated Care Pathway[5], after January 2009. If the classification is not specifically noted in patient record, then if one of the following is implied by the record, it should be considered as an indication of Stage 2:
    - Difficulty managing food and/or liquids
    - Choking episodes

or

- Patient first met the criteria for **<u>at least</u> Stage 2 Mild to Moderate Speech Changes**, based on the MND Scotland Integrated Care Pathway[5], after January 2009. If the classification is not specifically noted in patient record, then if one of the following is implied by the record, it should be considered as an indication of Stage 2:
    - Mild to moderate dysarthria (difficulty speaking)
    - Ability to talk in full sentences is diminished
    - Increased severity of all symptoms (may include slurring, hoarseness, reduced vocal intensity, nasality)

or

- Patient first met the criteria for **<u>at least</u> Stage 2 Mild Respiratory Symptoms**, based on the MND Scotland Integrated Care Pathway[5], after January 2009. If the classification is not specifically noted in patient record, then if one of the following is implied by the record, it should be considered as an indication of Stage 2:
    - Shortness of breath on moderate activity
    - Pooling oral secretions
    - Cough is diminished but patient is able to move secretions with some effort
    - Day time fatigue

<u>Exclusion Criteria:</u>

1. Patients to whom the Adults with Incapacity Act[6] applies, according to the knowledge of the Hospice clinical team responsible for their care
2. Patients who are profoundly or acutely confused based on the professional clinical judgment of the Hospice clinical team responsible for their care
3. Patients who are too unwell to participate based on the professional clinical judgment of the Hospice clinical team responsible for their care
4. Patients' or families' emotional state suggests it would be inappropriate to approach the patient at this time based on the professional clinical judgment of the Hospice clinical team responsible for their care

Recruitment:

Patients of the Edwina Bradley Day Hospice who met the eligibility criteria, were contacted by one of the Edwina Bradley Day Hospice staff while in the Hospice during their regular visits at the Day Hospice and offered the opportunity to participate in this audit. Recruitment period for Day Hospice patients was between July 16th and August 16th 2012.

Patients receiving care from the Community Specialist Palliative Care Team, who met the eligibility criteria, were contacted by the Clinical Nurse Specialists during their regular home visits and offered the opportunity to participate in this audit. There are three Clinical Nurse Specialists employed by the Hospice. During the period of July 23rd and August 10th 2012 the three nurses took alternate weeks to recruit patients from those they were scheduled to visit within that week.

Obtaining consent:

Patients of the Edwina Bradley Day Hospice were contacted by one of the Edwina Bradley Day Hospice staff while in the Hospice during their regular visits at the Day Hospice and offered the opportunity to participate in this audit. Patients, who were interested in participating, were given a copy of the Patient Information Leaflet (see **Appendix 2**, page 78) to read. If the patient decided to participate, one of the audit coordinators went through the main points of the Patient Information Leaflet again along with the patient and the patient was asked to sign a Consent Form (see **Appendix 3**, page 87). If the patient was unable to read the Patient Information Leaflet, then one of the Audit Coordinators verbally described the information contained within the leaflet before asking the patient to sign a Consent Form.

The patients receiving care from the Community Specialist Palliative Care Team were approached by the Clinical Nurse Specialist during one of her regular visits. The Clinical Nurse Specialist discussed the main aims, the voluntary nature of participation and the procedure of the audit and asked the patient if he/she would be interested in participating. If the patient agreed, the Clinical Nurse Specialist gave them a Patient Information Leaflet and asked for their permission to allow one of the audit coordinators to contact them by phone to arrange a visit at the patient's home. The audit coordinators then confirmed by telephone that the patient was still interested in participating and arranged a visit. During that visit, the same procedure used for patients of the Edwina Bradley Day Hospice was used to obtain patient consent.

Hospice staff involved in recruiting patients in the Edwina Bradley Day Hospice and in the community were provided with specific instructions detailing how to proceed with selection, recruitment and consent (see **Appendix 4**, page 89, and **Appendix 5**, page 91). Hospice staff stressed to the patients that participation was voluntary and that, if they did not wish to participate, this would not affect their care in any way. Patients were offered time to consider whether or not they wished to participate.

Data collection:

The patients of the Edwina Bradley Day Hospice who consented to participate in the audit were offered a private and quiet space to complete the Questionnaire. One of the audit coordinators read the questions and answer options aloud to them and marked their choice of answer.

During the audit coordinators' visit to the patients receiving care from the Community Specialist Palliative Care Team, the same procedure outlined above was used in order to complete the Questionnaire.

All patients were made aware that they had the right to choose not to answer any of the questions and to withdraw from the audit at any time as specified in the Patient Information Leaflet and Consent Form. **Figures 1 and 2** present the number of patients approached for this audit and the number of patients who finally participated in data collection.

Figure 1: Flowchart indicating how the final Day Hospice patient sample participating in data collection was selected.

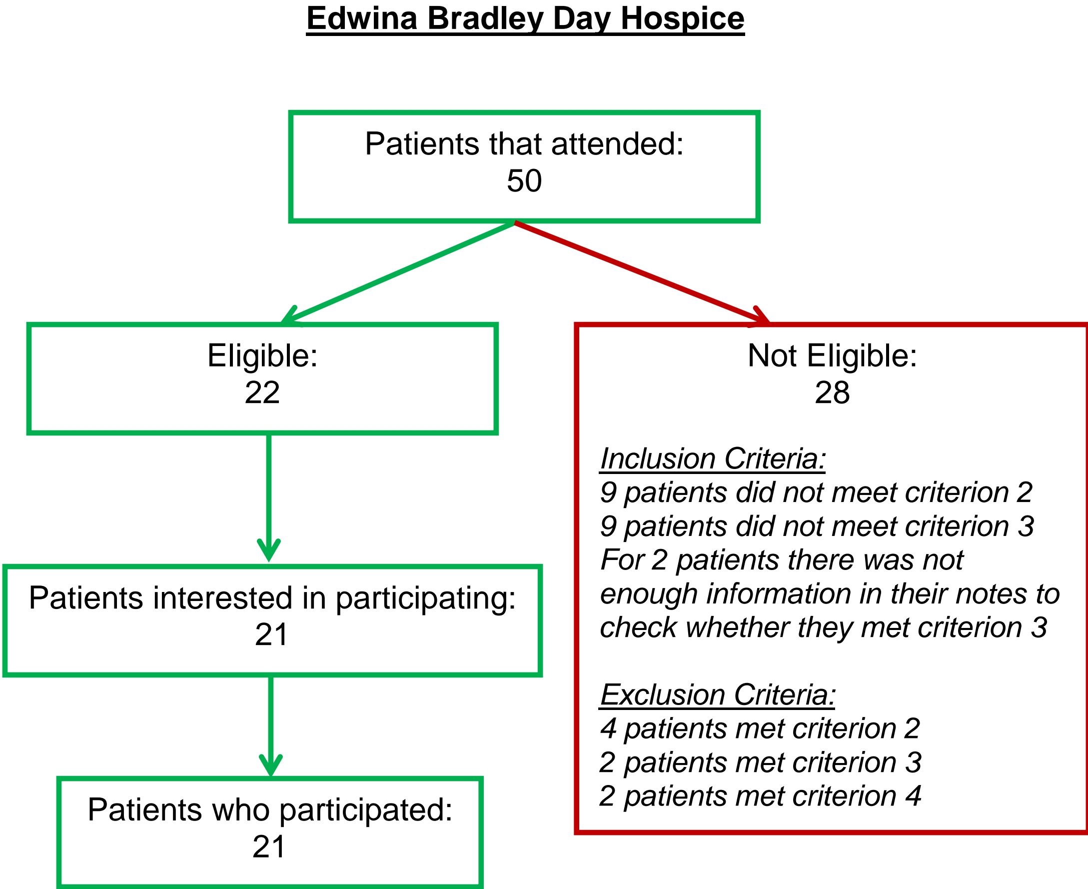
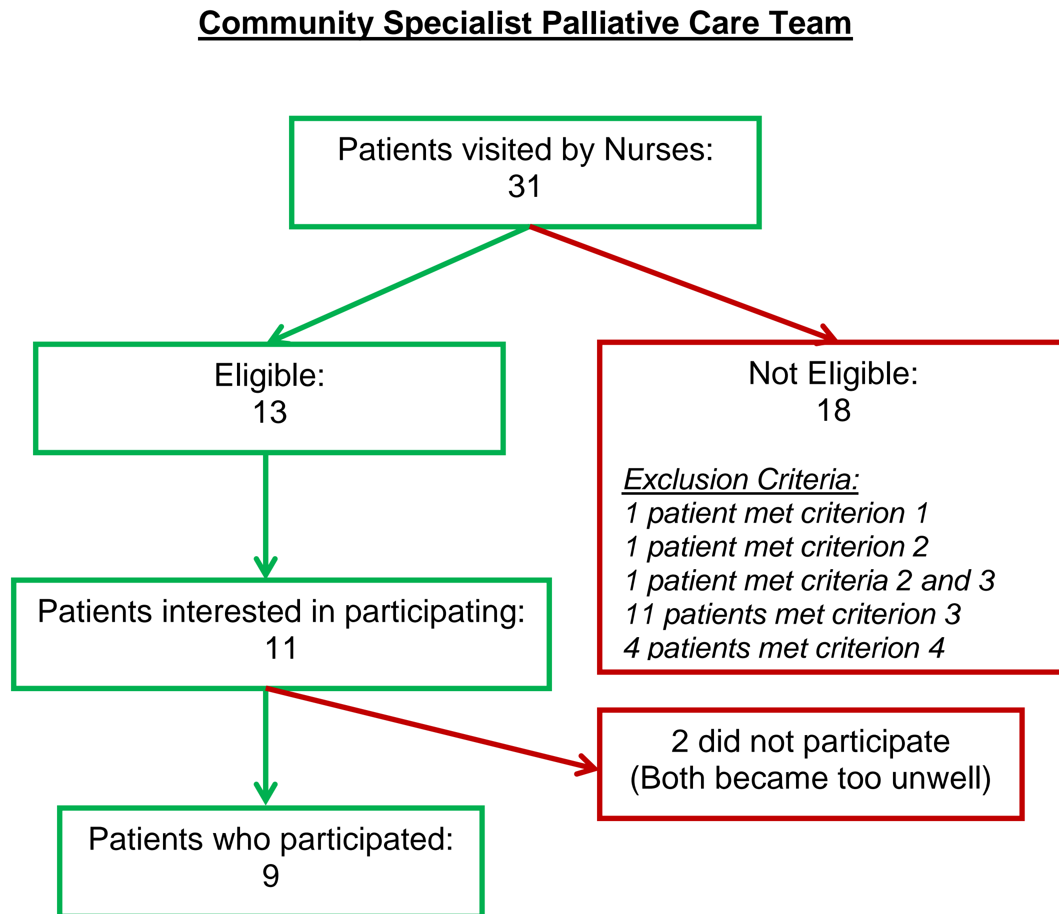


Figure 2: Flowchart indicating how the final community patient sample participating in data collection was selected.



Maintaining Confidentiality:

Two copies of the Consent Forms were attached to the Questionnaire. The patients were asked to sign both forms. One copy of the Consent Form was given to the patient and the other remained attached to the Questionnaire. A photocopy of the Consent Form was included in the patient's notes. Identifying information including the patient's first and last name and date of birth were included on the Consent Form but not on the Questionnaire itself. As part of the Consent Form, the patients were also asked to complete the name of their General Practitioner (GP) and the name of their Practice. This information was used to contact the GP via mail (see **Appendix 6**, page 93) to inform them that the patient had taken part in the audit in case the patient subsequently needed support or had any questions or concerns. Specific permission was obtained for this from the patients as part of the Consent Form. The GPs who were contacted did not receive any information relating to the patients' answers. As part of the Consent Form, patients were given the opportunity to provide a contact address if they wanted to receive a copy of the results of the audit.

After each Questionnaire was completed, both the Questionnaire and Consent Form were allocated an identification number unique to each participant by the audit coordinators. Identification numbers were given in a sequential order based on when each patient completed the Questionnaire. All data from the Questionnaire were entered in an excel spreadsheet containing no identifying information. Subsequently, the Questionnaires and Consent Forms were given to an allocated member of the audit team who entered all the identifiable patient information (name and age) on a separate excel spreadsheet connecting this identifiable information with the unique identification number for each patient. The list connecting the identification numbers with the patient identifiable information was kept separately from any other audit data and stored securely in a desktop computer in the Hospice to which only the above allocated staff member has access. The allocated member of staff will access the addresses provided on the Consent Forms by the participants wishing to see a copy of the audit results after the end of the audit in order to mail the results.

The patient Questionnaire included a box which patients could select if they wished to be contacted by a member of staff to discuss any questions or concerns that arose after taking part in the audit. If a patient selected this box or if the audit coordinators entering the Questionnaire data believed that information written in the Questionnaire indicated potential for serious harm to the patient or others, they would ask a senior clinician of the Hospice to contact the patient. If the senior clinician believed that there was a likelihood of harm to the patient or others, then the patient's GP would also have had to be notified along with other relevant authorities.

Data Analysis:

Only the data from the first of the two Questionnaires completed by participants involved in testing the intra-participant variability of the Questionnaire was used in data entry and analysis. Out of the data collected from the first six participants that tested the Questionnaire, only the data from the questions that were not amended after testing were used for data analysis. Data from questions that were later amended were treated as missing data for data analysis purposes. Additionally, on a few occasions patients were unable to select only one of the answers to a question because none or more than one answer applied to them. For such questions their data were entered as missing.

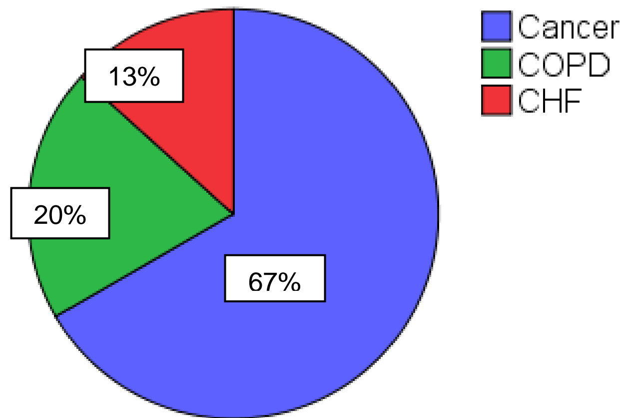
Statistical analysis was conducted using the Statistical Package for the Social Sciences (SPSS version 18). Descriptive statistics were calculated for the sample included in the audit and frequencies of the patients' answers to each question were calculated and presented in charts. Further analysis required the use of cross-tabulations in order to compare different subgroups within our sample based on gender (male/female), diagnosis (cancer/COPD and CHF) and age (49-72 years/73-95 years) even though the statistical significance of these comparisons was impossible to determine given the small sample size of each subgroup. Cross-tabulations were run for Questions 1, 4, 5, 8, 9, 10, 11, 12, 13, and 14. Differences in percentages of answers more than 35% between groups were considered worth discussing.

Results:

Description of the sample:

The data from a total of 30 patients were included in the statistical analysis. Of these, 50% were female. The mean age was 73.9 years (± 10.9 years, range 49-95 years). Of the patients participating, 20 (67%) had a diagnosis of cancer, 6 (20%) a diagnosis of COPD and 4 (13%) a diagnosis of CHF. **Figure 3** shows a pie-chart of the percentages of patients with each diagnosis.

Figure 3: Percentages of patients under different diagnoses. (N=30)



In order to better explore the data relating to each Action Point, patients were successively split into different groups based on gender (male/female), diagnosis (cancer/COPD and CHF) and age (49-72 years/73-95 years). **Table 1** presents the characteristics of the different groups. Cross-tabulations using these groups were run for questions 1, 4, 5, 8, 9, 10, 11, 12, 13, and 14. Results of these will be presented underneath the relevant questions.

Table 1: Patient characteristics when split into two groups based on diagnosis (cancer/COPD and CHF), gender (male/female) and age (49-72 years/73-95 years)

	Cancer	**COPD and CHF**
N	20	10
Male	50%	50%
Female	50%	50%
Age (49-72)	30%	90%
Age (73-95)	70%	10%

	Male	**Female**
N	15	15
Cancer	66.7%	66.7%
COPD and CHF	33.3%	33.3%
Age (49-72)	46.7%	53.3%
Age (73-95)	53.3%	46.7%

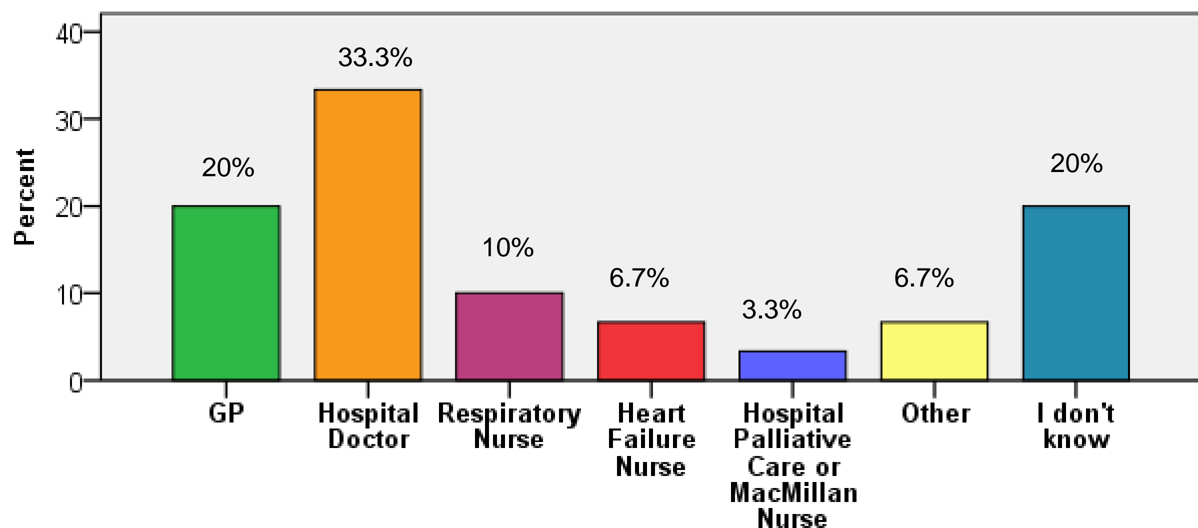
	Age (49-72)	**Age (73-95)**
N	15	15
Cancer	40%	93.3%
COPD and CHF	60%	6.7%
Male	46.7%	53.3%
Female	53.3%	46.7%

Action Point 2:

Action Point 2 recommended that “NHS Boards, through palliative care networks and CHPs, should ensure that patients identified with palliative and end of life care needs are appropriately assessed and reviewed in all care setting using recognized tools currently available”.[1 (p.10)]

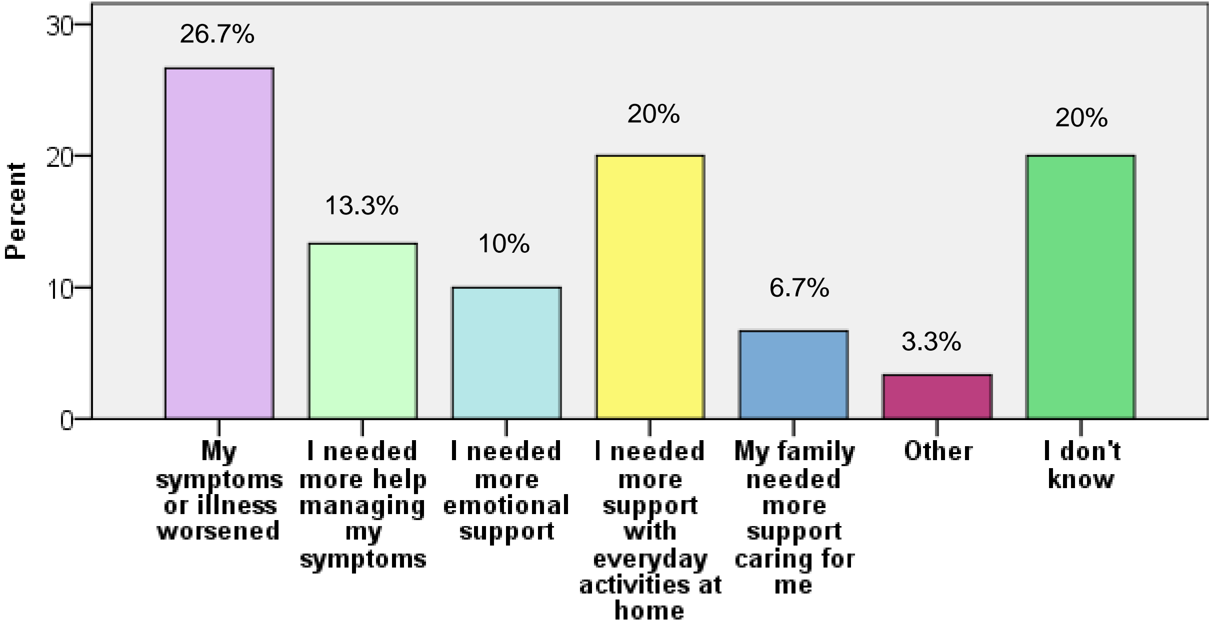
There were a total of three questions assessing Action Point 2 in the Questionnaire. The first of these (Question 2) asked participants who they thought was the first healthcare professional that identified them as having palliative needs. **Figure 4** presents the percentage of the patients selecting each of the answer options. The two patients who chose “other”, mentioned that it was someone from the social services or a relative who is a healthcare professional that first identified them as having palliative needs.

Figure 4: Patient perception of who first identified them as having palliative needs. (N=30). *[Please note that an option of “Community MacMillan Nurse” was available however no patient chose that option]*



The second question assessing Action Point 2 (Question 3) asked the participants what they thought was the main thing that had changed for them at the time they were identified as having palliative needs. **Figure 5** provides an illustration of the percentage of participants choosing each answer. The patient who chose "other" explained that their main issue at the time was social isolation.

Figure 5: Patient perception of what had changed for them at the time they were identified as having palliative needs. (N=30).
[Please note that an option of "I needed more support with finances" was available however no patient chose that option]



The final question assessing Action Point 2 (Question 4) enquired whether patients had been asked by a healthcare professional how they were coping with their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. The answers to this question are illustrated in **Figure 6**. For the patients who answered that one or more of their palliative holistic needs were assessed, there was a follow-up question (Question 4a) enquiring whether they felt their needs were assessed regularly enough. Answers are illustrated in **Figure 7**.

Figure 6: Patient perception of whether they had been asked by a healthcare professional how they were coping with their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs.

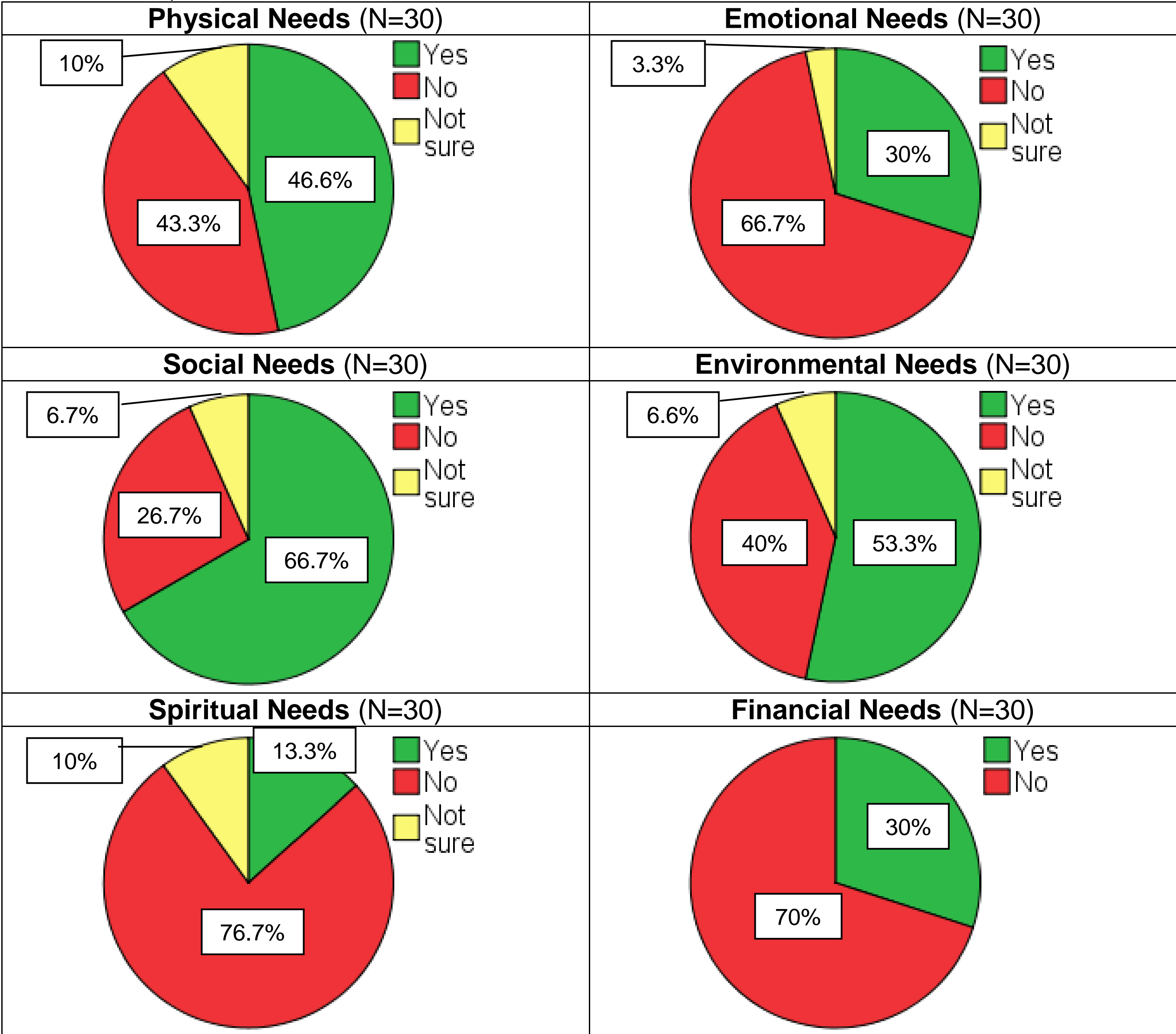
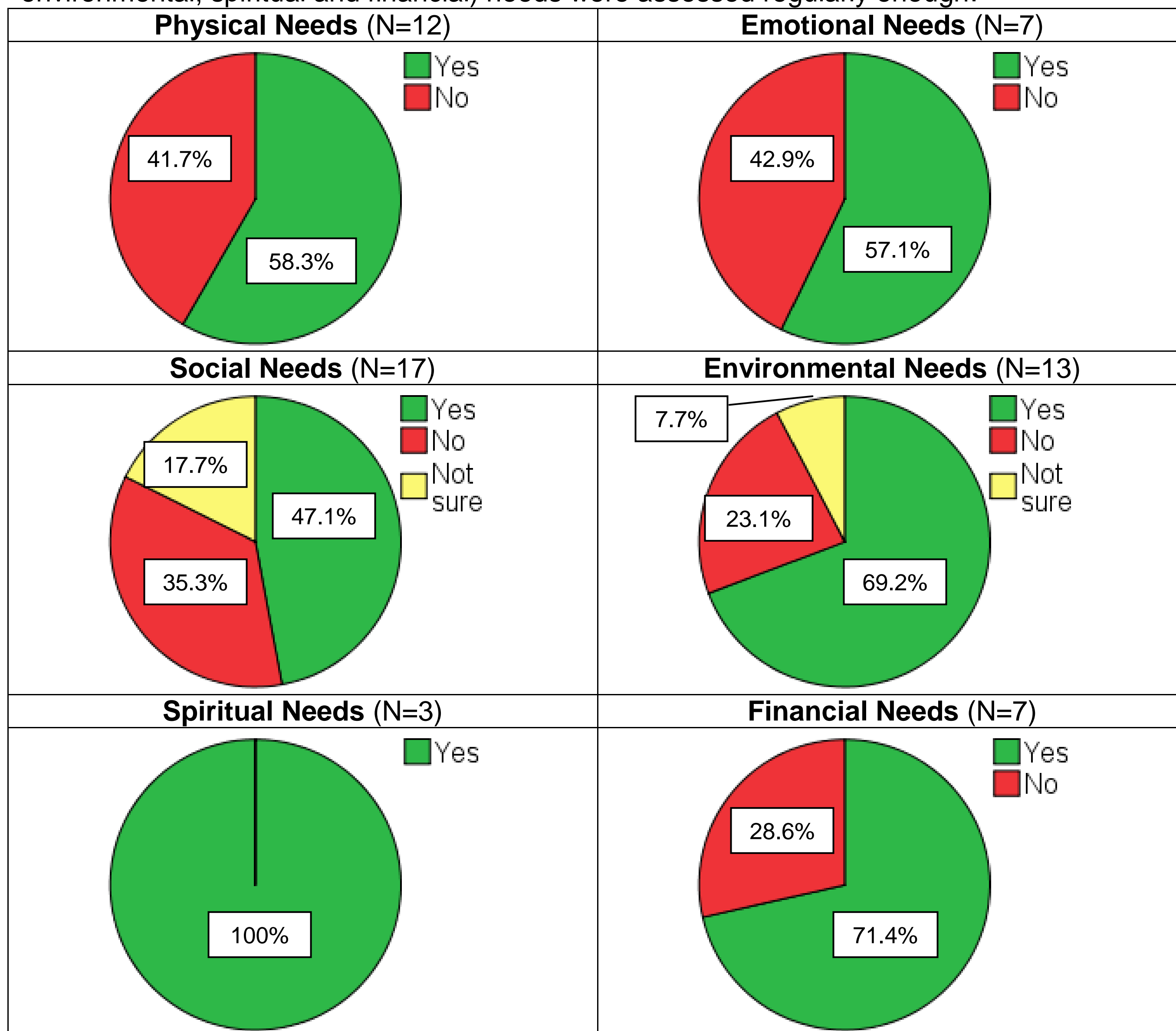


Figure 7: For those patients who said they had been asked how they were coping with their needs, this figure presents patient perception of whether their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs were assessed regularly enough.



Further analysis of the data relating to this Action Point was undertaken using cross-tabulations of Question 4 for the patients split into groups based on gender (male/female), diagnosis (cancer/COPD and CHF) and age (49-72 years/73-95 years). **Tables 2, 3 and 4** present these results. The only remarkable finding was for physical needs when groups were split by gender when 73% (11 out of 15) of males said that they were asked how they were coping with their physical needs in comparison to 20% (3 out of 15) of females.

Table 2: Cross-tabulations by gender: patient perception of whether they had been asked by a healthcare professional how they were coping with their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. *(Green indicates differences between groups greater than 35%)*

	Physical Needs		**Emotional Needs**	
	Female (N=15)	***Male*** (N=15)	***Female*** (N=15)	***Male*** (N=15)
Yes	20%	73.3%	26.7%	33.3%
No	66.7%	20%	73.3%	60%
Not Sure	13.3%	6.7%	0%	6.7%
	Social Needs		**Environmental Needs**	
	Female (N=15)	***Male*** (N=15)	***Female*** (N=15)	***Male*** (N=15)
Yes	53.3%	80%	46.7%	60%
No	40%	13.3%	46.7%	33.3%
Not Sure	6.7%	6.7%	6.7%	6.7%
	Spiritual Needs		**Financial Needs**	
	Female (N=15)	***Male*** (N=15)	***Female*** (N=15)	***Male*** (N=15)
Yes	13.3%	13.3%	20%	40%
No	80%	73.3%	80%	60%
Not Sure	6.7%	13.3%	0%	0%

Table 3: Cross-tabulations by diagnosis: patient perception of whether they had been asked by a healthcare professional how they were coping with their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. No differences worth noting were found between groups for this question.

	Physical Needs		**Emotional Needs**	
	Cancer (N=20)	***COPD or CHF*** (N=10)	***Cancer*** (N=20)	***COPD or CHF*** (N=10)
Yes	40%	60%	30%	30%
No	45%	40%	70%	60%
Not Sure	15%	0%	0%	10%
	Social Needs		**Environmental Needs**	
	Cancer (N=20)	***COPD or CHF*** (N=10)	***Cancer*** (N=20)	***COPD or CHF*** (N=10)
Yes	60%	80%	50%	60%
No	30%	20%	40%	40%
Not Sure	10%	0%	10%	0%
	Spiritual Needs		**Financial Needs**	
	Cancer (N=20)	***COPD or CHF*** (N=10)	***Cancer*** (N=20)	***COPD or CHF*** (N=10)
Yes	20%	0%	30%	30%
No	70%	90%	70%	70%
Not Sure	10%	10%	0%	0%

Table 4: Cross-tabulations by age: patient perception of whether they had been asked by a healthcare professional how they were coping with their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. No differences worth noting were found between groups for this question.

	Physical Needs		**Emotional Needs**	
	49-72 years (N=15)	***73-95 years*** (N=15)	***49-72 years*** (N=15)	***73-95 years*** (N=15)
Yes	46.7%	46.7%	26.7%	33.3%
No	46.7%	40%	66.7%	66.7%
Not Sure	6.7%	13.3%	6.7%	0%
	Social Needs		**Environmental Needs**	
	49-72 years (N=15)	***73-95 years*** (N=15)	***49-72 years*** (N=15)	***73-95 years*** (N=15)
Yes	66.7%	66.7%	53.3%	53.3%
No	33.3%	20%	46.7%	33.3%
Not Sure	0%	13.3%	0%	13.3%
	Spiritual Needs		**Financial Needs**	
	49-72 years (N=15)	***73-95 years*** (N=15)	***49-72 years*** (N=15)	***73-95 years*** (N=15)
Yes	13.3%	13.3%	33.3%	26.7%
No	86.7%	66.7%	66.7%	73.3%
Not Sure	0%	20%	0%	0%

Action Point 4:

Action Point 4 recommended that "CHPs, palliative care networks, older peoples services and LTC teams in each NHS board area should collaborate to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person-centred and responsive to the needs of the diversity of the population at appropriate stages of the patient journey".[1.(p.15)]

Action Point 4 was assessed using seven questions. Question 1 asked the patients whether they felt that their illness was fully explained to them by a healthcare professional in a way they could understand. Participant answers are illustrated in **Figure 8**. The patients who answered yes to the aforementioned question were subsequently asked who it was that first explained their illness to them in a way that they could understand (Question 1a). A total of 15 patients answered this question. Of these, 13.3% said it was their GP who first explained their illness to them and 86.7% said it was a hospital doctor (**Figure 9**). Cross-tabulations of Question 1 for gender, diagnosis and age are presented in **Table 5**.

Figure 8: Patient perception of whether their illness was fully explained to them by a healthcare professional in way that they could understand. (N=23)

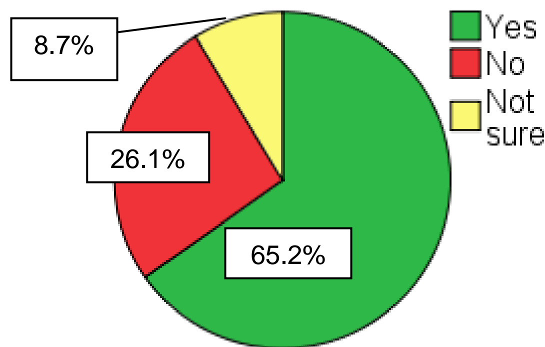


Figure 9: For those patients who said that their illness was fully explained to them by a healthcare professional in a way that they could understand, this figure shows patient perception of who that healthcare professional was. (N=15)

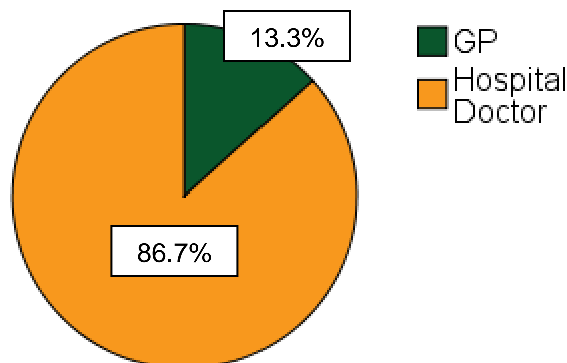
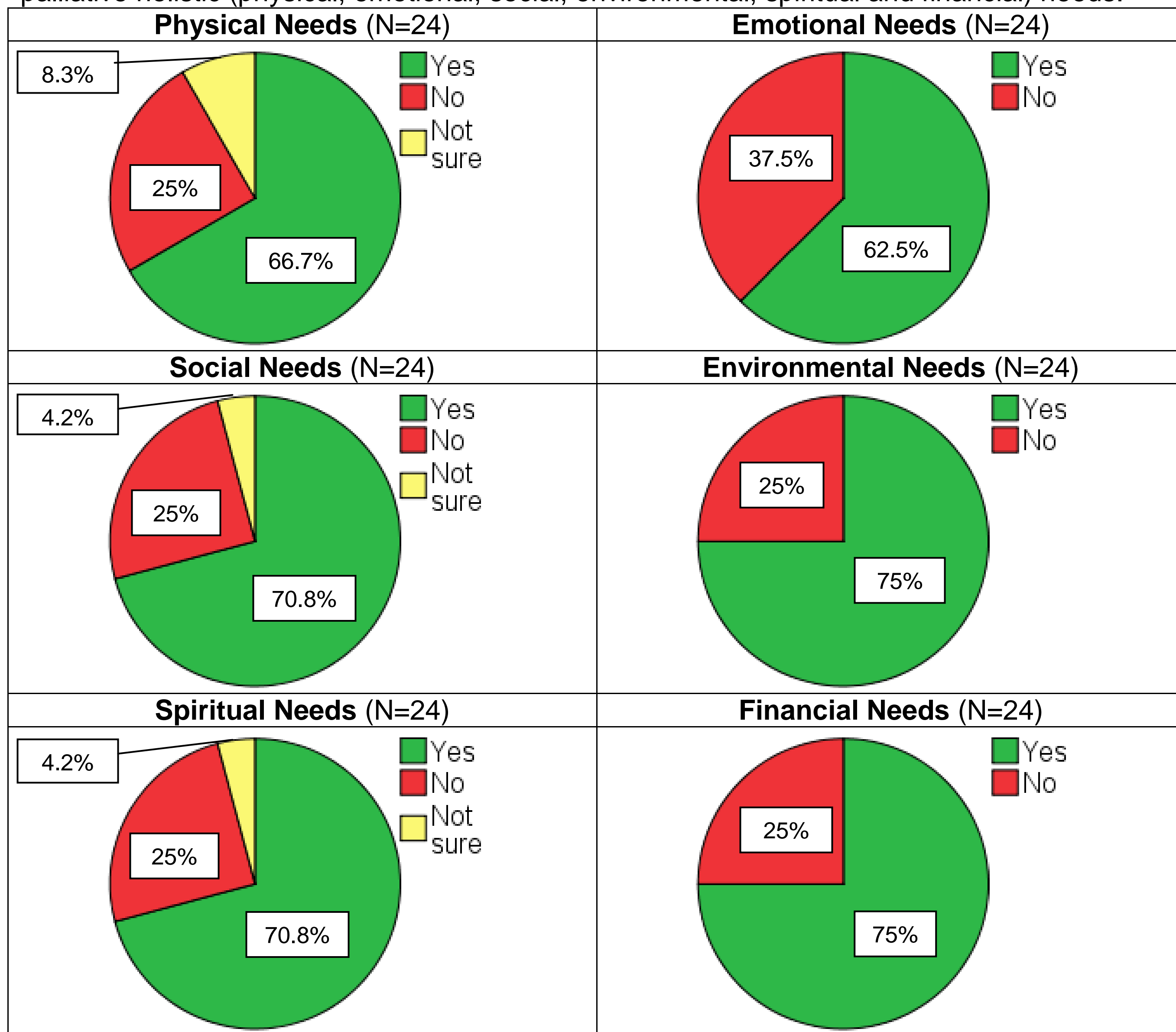


Table 5: Cross-tabulations by gender, diagnosis and age: Patient perception of whether their illness was fully explained to them by a healthcare professional in way that they could understand. No differences worth noting were found between groups for this question.

Gender		
	Female (N=9)	***Male*** (N=14)
Yes	44.4%	78.6%
No	33.3%	21.4%
Not Sure	22.2%	0%
Diagnosis		
	Cancer (N=15)	***COPD or CHF*** (N=8)
Yes	60%	75%
No	26.7%	25%
Not Sure	13.3%	0%
Age		
	49-72 years (N=10)	***73-95 years*** (N=13)
Yes	70%	61.5%
No	30%	23.1%
Not Sure	0%	15.4%

The second question (Question 5) assessing Action Point 4 inquired whether patients felt that they had received sufficient help or advice to meet their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. **Figure 10** presents the findings.

Figure 10: Patient perception of whether they received enough help or advice to meet their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs.



Further analysis of the data relating to Question 5 was undertaken using cross-tabulations of for the patients split into groups based on gender (male/female), diagnosis (cancer/COPD and CHF) and age (49-72 years/73-95 years). These cross-tabulations are presented in **Tables 6, 7 and 8**. Differences worth noting were observed in two cases. When patients were split into groups based on diagnosis, 87.5% (14 out of 16) of patients with a diagnosis of cancer felt that they had received sufficient help or advice to meet their financial needs compared to 50% (4 out of 8) of patients with a diagnosis of COPD or CHF. The same percentage of patients with a diagnosis of cancer felt that they had received sufficient help with their spiritual needs compared to only 37.5% (3 out of 8) of patients with COPD or CHF. When patients were split into groups based on age, noticeably more patients in the 73-95 year group said that they had received sufficient help or advice to meet all of their palliative needs compared to the patients in the 49-72 year group [physical needs 85.7% (12) versus 40% (4); emotional needs 78.6% (11) versus 40% (4), social needs 85.7% (12) versus 50% (5), environmental needs 85.7% (12) versus 60% (6), spiritual needs 87.5% (12) versus 50% (5), and financial needs 92.9% (13) versus 50% (5)].

Table 6: Cross-tabulations by gender: Patient perception of whether they received enough help or advice to meet their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. No differences worth noting were found between groups for this question.

	Physical Needs		**Emotional Needs**	
	Female (N=10)	***Male*** (N=14)	***Female*** (N=10)	***Male*** (N=14)
Yes	60%	71.4%	50%	71.4%
No	30%	21.4%	50%	28.6%
Not Sure	10%	7.1%	0%	0%
	Social Needs		**Environmental Needs**	
	Female (N=10)	***Male*** (N=14)	***Female*** (N=10)	***Male*** (N=14)
Yes	70%	71.4%	90%	64.3%
No	30%	21.4%	10%	35.7%
Not Sure	0%	7.1%	0%	0%
	Spiritual Needs		**Financial Needs**	
	Female (N=10)	***Male*** (N=14)	***Female*** (N=10)	***Male*** (N=14)
Yes	70%	71.4%	70%	78.6%
No	20%	28.6%	30%	21.4%
Not Sure	10%	0%	0%	0%

Table 7: Cross-tabulations by diagnosis: Patient perception of whether they received enough help or advice to meet their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. *(Green indicates differences between groups greater than 35%)*

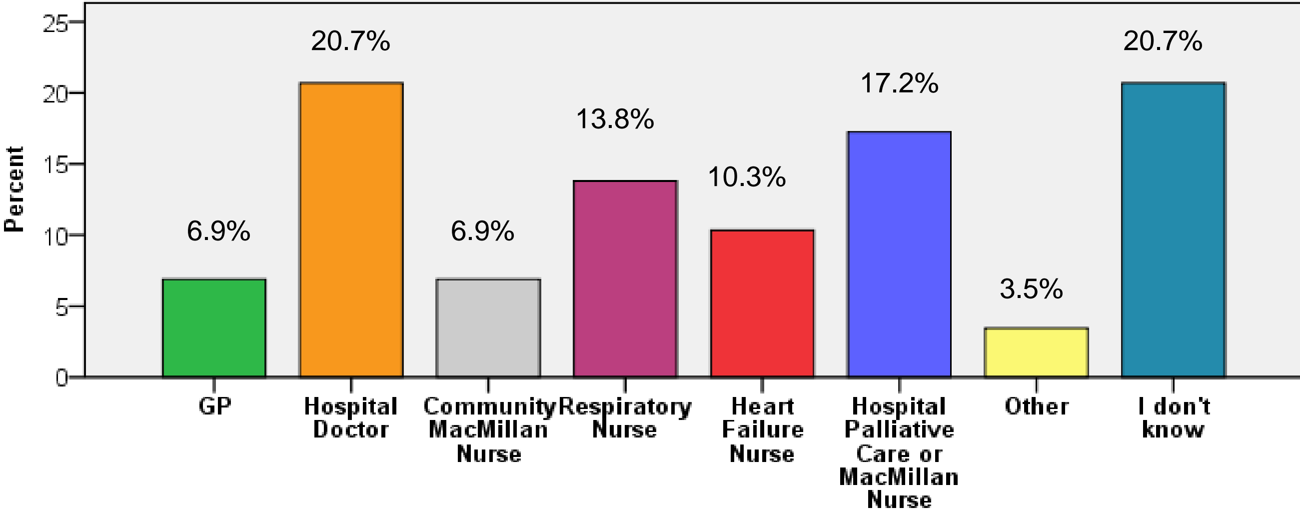
	Physical Needs		**Emotional Needs**	
	Cancer (N=16)	***COPD or CHF*** (N=8)	***Cancer*** (N=16)	***COPD or CHF*** (N=8)
Yes	75%	50%	68.8%	50%
No	18.8%	37.5%	31.3%	50%
Not Sure	6.2%	12.5%	0%	0%
	Social Needs		**Environmental Needs**	
	Cancer (N=16)	***COPD or CHF*** (N=8)	***Cancer*** (N=16)	***COPD or CHF*** (N=8)
Yes	75%	62.5%	81.3%	62.5%
No	25%	25%	18.8%	37.5%
Not Sure	0%	12.5%	0%	0%
	Spiritual Needs		**Financial Needs**	
	Cancer (N=16)	***COPD or CHF*** (N=8)	***Cancer*** (N=16)	***COPD or CHF*** (N=8)
Yes	87.5%	37.5%	87.5%	50%
No	12.5%	50%	12.5%	50%
Not Sure	0%	12.5%	0%	0%

Table 8: Cross-tabulations by age: Patient perception of whether they received enough help or advice to meet their palliative holistic (physical, emotional, social, environmental, spiritual and financial) needs. *(Green indicates differences between groups greater than 35%)*

	Physical Needs		**Emotional Needs**	
	49-72 years (N=10)	***73-95 years*** (N=14)	***49-72 years*** (N=10)	***73-95 years*** (N=14)
Yes	40%	85.7%	40%	78.6%
No	50%	7.1%	60%	21.4%
Not Sure	10%	7.1%	0%	0%
	Social Needs		**Environmental Needs**	
	49-72 years (N=10)	***73-95 years*** (N=14)	***49-72 years*** (N=10)	***73-95 years*** (N=14)
Yes	50%	85.7%	60%	85.7%
No	40%	14.3%	40%	14.3%
Not Sure	10%	0%	0%	0%
	Spiritual Needs		**Financial Needs**	
	49-72 years (N=10)	***73-95 years*** (N=14)	***49-72 years*** (N=10)	***73-95 years*** (N=14)
Yes	50%	85.7%	50%	92.9%
No	50%	7.1%	50%	7.1%
Not Sure	0%	7.1%	0%	0%

Question 7 of the Questionnaire also assessed Action Point 4. It asked patients who first referred them to St Margaret of Scotland Hospice. Answers are presented in **Figure 11**. Of the two patients that answered "other, one said that a referral was made by a social worker and the other patient contacted the Hospice directly as there were pre-existing links due to the illness of another family member.

Figure 11: Patient perception of who was the healthcare professional that first referred them to St Margaret of Scotland Hospice. (N=29)



Subsequently, patients were asked if they remember being told about their referral to the Hospice (Question 8). The patients who answered “yes”, were then asked if they remember the person who referred them to the Hospice explaining why they thought the patient would benefit from this referral (Question 8a). **Figure 12** presents the answers to these questions. **Table 9** presents the results of cross-tabulation based on gender, diagnosis and age for Question 8.

Figure 12: Patient perception of the provision of information relating to their referral to St Margaret of Scotland Hospice

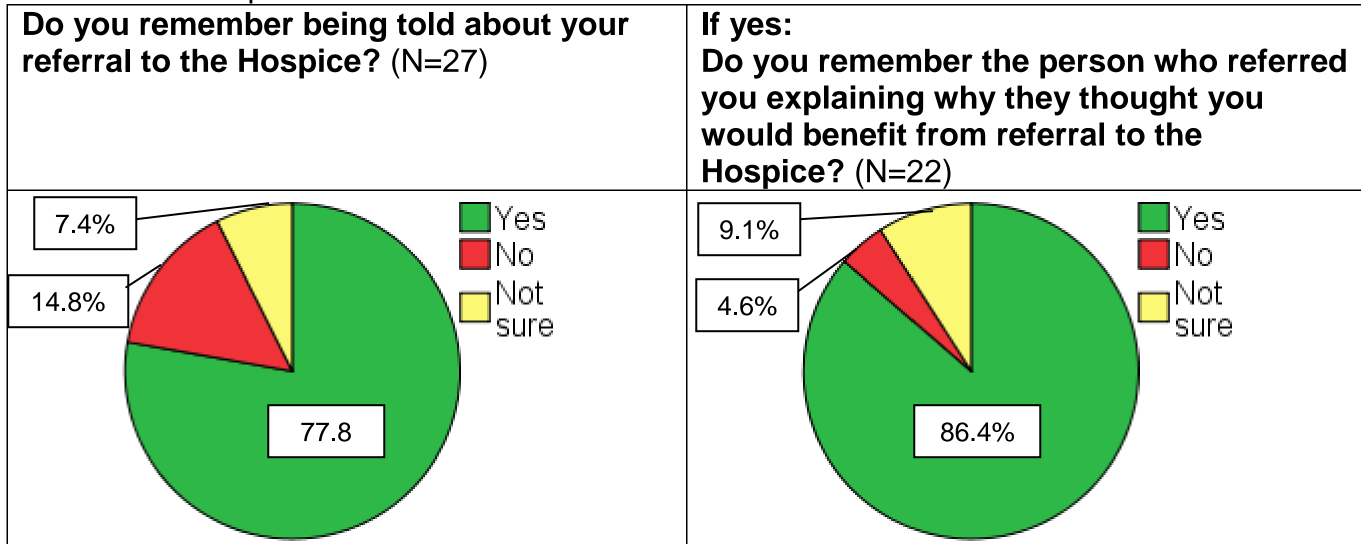
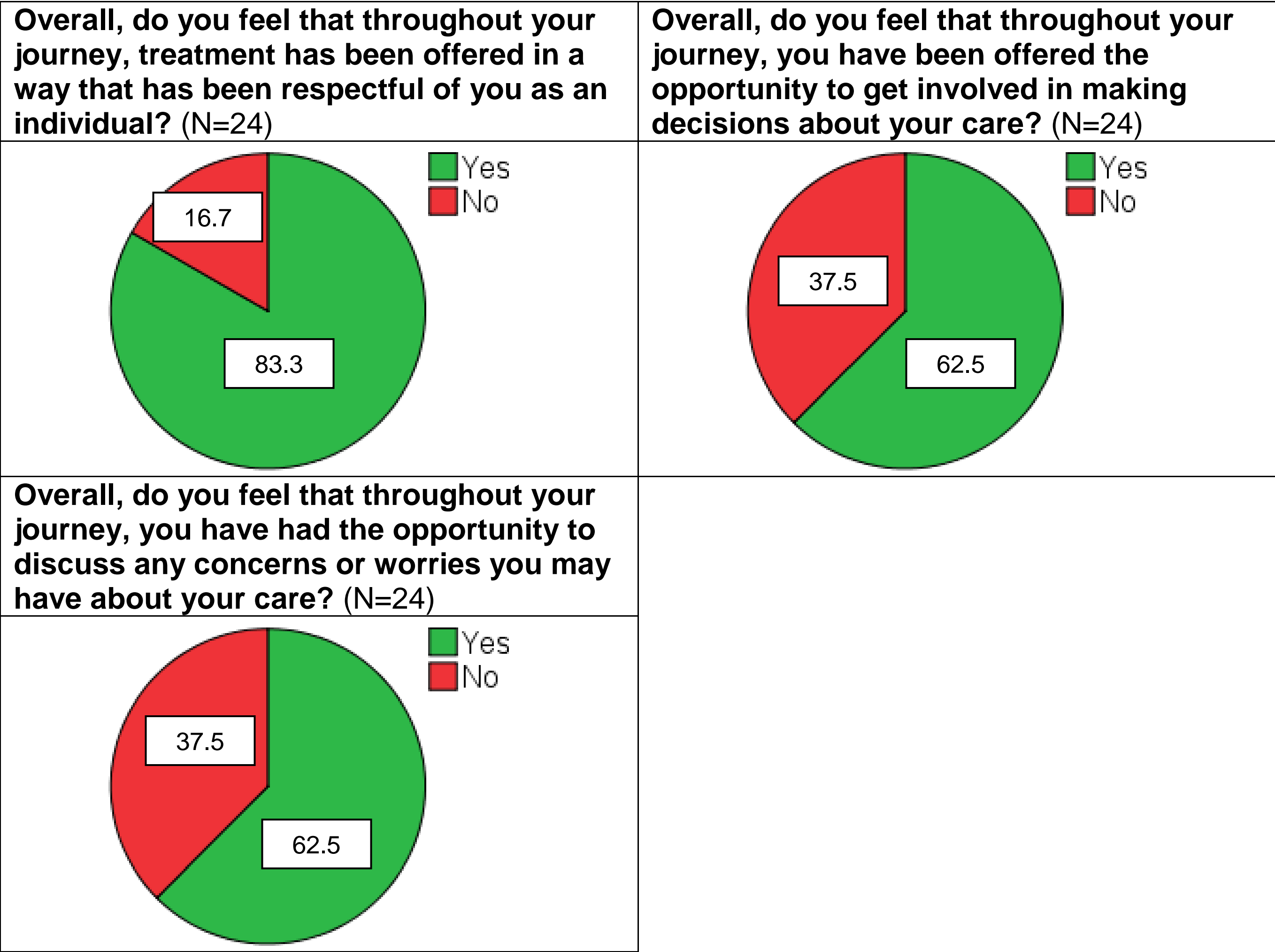


Table 9: Cross-tabulations by gender, diagnosis and age: Patient perception of whether they had been told about their referral to St. Margaret of Scotland Hospice. No differences worth noting were found between groups for this question.

	Gender	
	Female (N=15)	***Male*** (N=12)
Yes	86.7%	66.7%
No	6.7%	25%
Not Sure	6.7%	8.3%
	Diagnosis	
	Cancer (N=17)	***COPD or CHF*** (N=10)
Yes	70.6%	90%
No	17.6%	10%
Not Sure	11.8%	0%
	Age	
	49-72 years (N=15)	***73-95 years*** (N=12)
Yes	86.7%	66.7%
No	13.3%	16.7%
Not Sure	0%	16.7%

The final three questions assessing Action Point 4 asked patients whether they felt that, throughout their journey, treatment had been offered in a way that was respectful to them as individuals (Question 12), whether they felt they had been offered the opportunity to get involved in making decisions about their care (Question 13), and whether they felt they had the opportunity to discuss any concerns or worries they might have had about their care (Question 14). **Figure 13** summarises patient answers to these questions.

Figure 13: Patient perception on whether, throughout their journey, care was offered in a person-centered manner.



Further analysis of the data to Questions 12, 13, and 14 was undertaken using cross-tabulations for the patients split into groups based on gender (male/female), diagnosis (cancer/COPD and CHF) and age (49-72 years/73-95 years). **Tables 10, 11 and 12** present these cross-tabulations. Noticeable differences were noted in Questions 13 and 14. When patients were split into groups based on diagnosis, 75% (12 out of 16) of patients with a diagnosis of cancer said that they have had the opportunity to discuss any concerns or worries they may have had about their care in comparison to 37.5% (3 out of 8) of patients with a diagnosis of COPD or CHF. When patients were split into groups based on age, 78.6% (11 out of 14) of patients in the 73-95 year group said they had been offered the opportunity to get involved in making decisions about their care and they had have had the opportunity to discuss any concerns or worries they may have had about their care in comparison to 40% (4 out of 10) of patients in the 49-72 year group.

Table 10: Cross-tabulations by gender, diagnosis and age: patient perception on whether their treatment was offered in a way that was respectful to them as individuals. No differences worth noting were found between groups for this question.

	Gender	
	Female (N=10)	***Male*** (N=14)
Yes	90%	78.6%
No	10%	21.4%
Not Sure	0%	0%
	Diagnosis	
	Cancer (N=16)	***COPD or CHF*** (N=8)
Yes	81.3%	87.5%
No	18.8%	12.5%
Not Sure	0%	0%
	Age	
	49-72 years (N=10)	***73-95 years*** (N=14)
Yes	80%	85.7%
No	20%	14.3%
Not Sure	0%	0%

Table 11: Cross-tabulations by gender, diagnosis and age: patient perception on whether they had been offered the opportunity to get involved in making decisions about their care. *(Green indicates differences between groups greater than 35%)*

	Gender	
	Female (N=10)	***Male*** (N=14)
Yes	60%	64.3%
No	40%	35.7%
Not Sure	0%	0%
	Diagnosis	
	Cancer (N=16)	***COPD or CHF*** (N=8)
Yes	68.8%	50%
No	31.3%	50%
Not Sure	0%	0%
	Age	
	49-72 years (N=10)	***73-95 years*** (N=14)
Yes	40%	78.6%
No	60%	21.4%
Not Sure	0%	0%

Table 12: Cross-tabulations by gender, diagnosis and age: patient perception on whether they had been offered the opportunity to discuss any concerns or worries they may have had about their care. *(Green indicates differences between groups greater than 35%)*

	Gender	
	Female (N=10)	***Male*** (N=14)
Yes	70%	57.1%
No	30%	42.9%
Not Sure	0%	0%
	Diagnosis	
	Cancer (N=16)	***COPD or CHF*** (N=8)
Yes	75%	37.5%
No	25%	62.5%
Not Sure	0%	0%
	Age	
	49-72 years (N=10)	***73-95 years*** (N=14)
Yes	40%	78.6%
No	60%	21.4%
Not Sure	0%	0%

Action Point 10:

Action Point 10 recommends that "NHS Boards should ensure that rapid access is available to appropriate equipment required for the care of those wishing to die at home from any advanced progressive condition."[1 (p.16)]

Action Point 10 was assessed using one main question (Question 6) with two sub-questions (Question 6a and 6b). These explored patients' need for and provision of adaptations or equipment in order to maintain their independence while at home. Out of the 30 patients participating, 90% (27) said that they had required adaptations or equipment to help them stay at home since their diagnosis and 10% (3) said that they did not. Subsequently, patients were asked how they acquired the adaptations or equipment that they needed. **Table 13** presents the patients' answers for each of the categories of adaptations and equipment commonly required and **Figure 14** presents a summary of this table. Under the "other" category, two patients mentioned that they needed a grab stick while one needed a feeding pump. Following this, patients who were provided with adaptations or equipment by social or healthcare services, were asked whether these were provided quickly enough to meet their needs (**Table 14** and its summary on **Figure 15**).

Table 13: Patient perception of their need for adaptations or equipment and of how they acquired what they needed.

	My family or I had it or had to buy it	**It was provided for me**	**Some I had or had to buy, some were provided**	**I needed this but it was not provided**
Walking aids (N=21)	19%	**66.7 %**	9.5%	4.8%
Mobility aids (N=14)	28.6%	**71.4%**	0%	0%
Aids to help you get in your home (N=16)	**56.3%**	25%	0%	18.8%
Toileting aids (N=16)	18.8%	**75%**	0%	6.3%
Bathing aids (N=19)	26.3%	**68.4%**	0%	5.3%
Bedroom aids (N=15)	26.7%	**53.3%**	0%	20%
Kitchen aids (N=10)	20%	**80%**	0%	0
Living room aids (N=15)	**73.3%**	20%	0%	6.7%
Adaptations to your home (N=16)	**50%**	43.8%	0%	6.3%
Other (N=3)	0%	**100%**	0%	0%

Figure 14: Summary of Table 1 indicating how those who required any kind of adaptations or equipment acquired them. (Based on a total of 169 entries for all adaptations and equipment mentioned in Table 1)

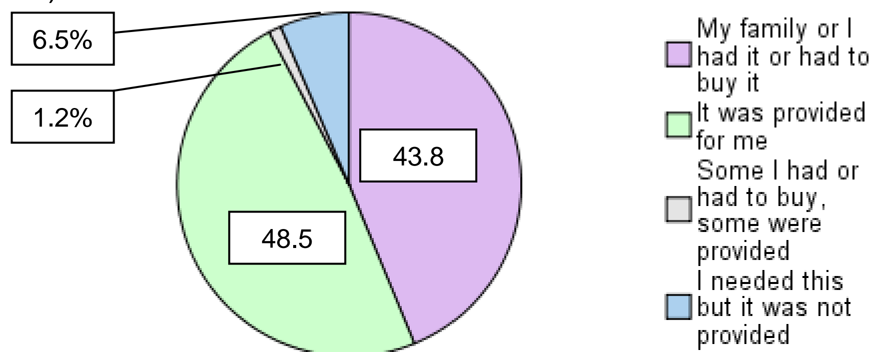
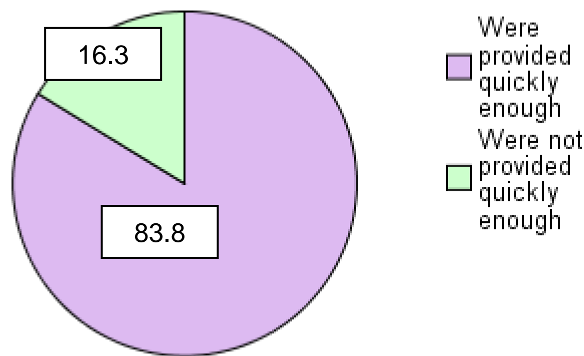


Table 14: For those patients who said they were provided with equipment or adaptations by the health or social care services, this table shows patient perception of whether the adaptations or equipment that were provided for them were provided quickly enough to meet their needs.

	Were provided quickly enough	**Were not provided quickly enough**
Walking aids (N=15)	**86.7%**	13.3%
Mobility aids (N=10)	**100%**	0%
Aids to help you get in your home (N=3)	**75%**	25%
Toileting aids (N=12)	**91.7%**	8.3%
Bathing aids (N=13)	**84.6%**	15.4%
Bedroom aids (N=8)	**75%**	25%
Kitchen aids (N=8)	**87.5%**	12.5%
Living room aids (N=3)	33.3%	**66.7%**
Adaptations to your home (N=7)	**71.4%**	28.6%
Other (N=3)	**100%**	0%

Figure 15: Summary of Table 3 indicating the percentage of equipment or adaptation that were provided in a timely manner. (Based on a total of 80 entries for all adaptations and equipment mentioned in Table 2)



Action Point 16:

Action Point 16 recommends that "NHS Boards should ensure that safe and effective processes, electronic or otherwise, are in place 24/7 to enable the transfer, to all relevant professionals and across sectoral and organizational boundaries of patient information as identified in the e-PCS regarding any patient identified as having palliative and end of life care needs and who gives consent".[1 (p.19)]

Action Point 16 was assessed using three questions concerning documents that aim to improve communication between patients, families and healthcare professionals. The first of these questions refers to the Anticipatory Care plan (ACP) (Question 9), the second to the Thinking Ahead Document (Question 10) and the last to the Electronic Palliative Care Summary (e-PCS) (Question 11). Each of these questions asked the patients whether they had ever heard of that document before and, if so, whether they already had or had begun making one (Questions 9a, 10a and 11a). **Figures 16, 17 and 18** show the patient answers to these questions.

Figure 16: Patient awareness of the ACP and opportunity to make one.

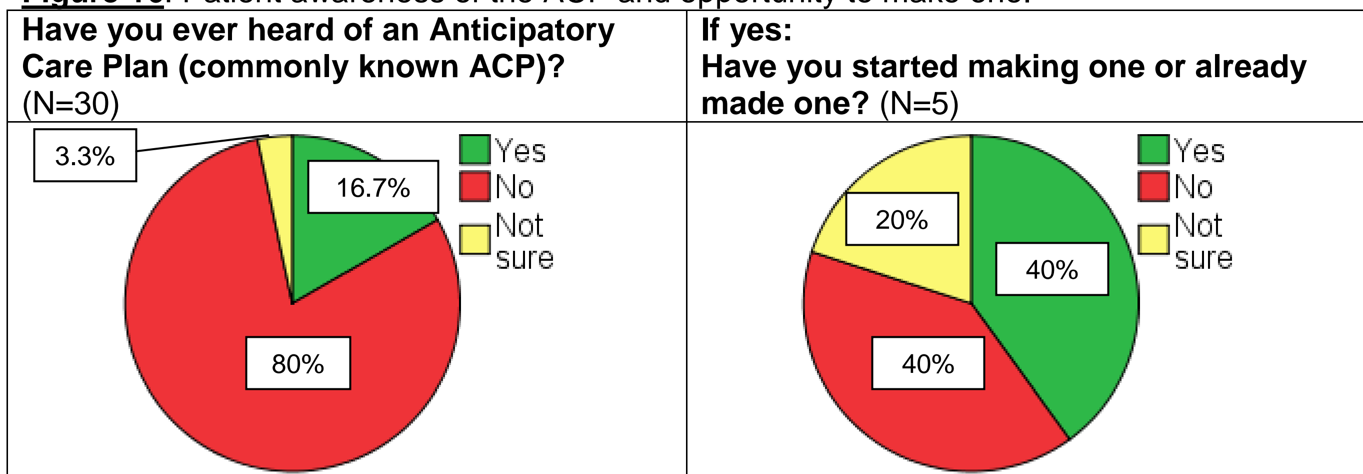


Figure 17: Patient awareness of the Thinking Ahead Document and opportunity to make one.

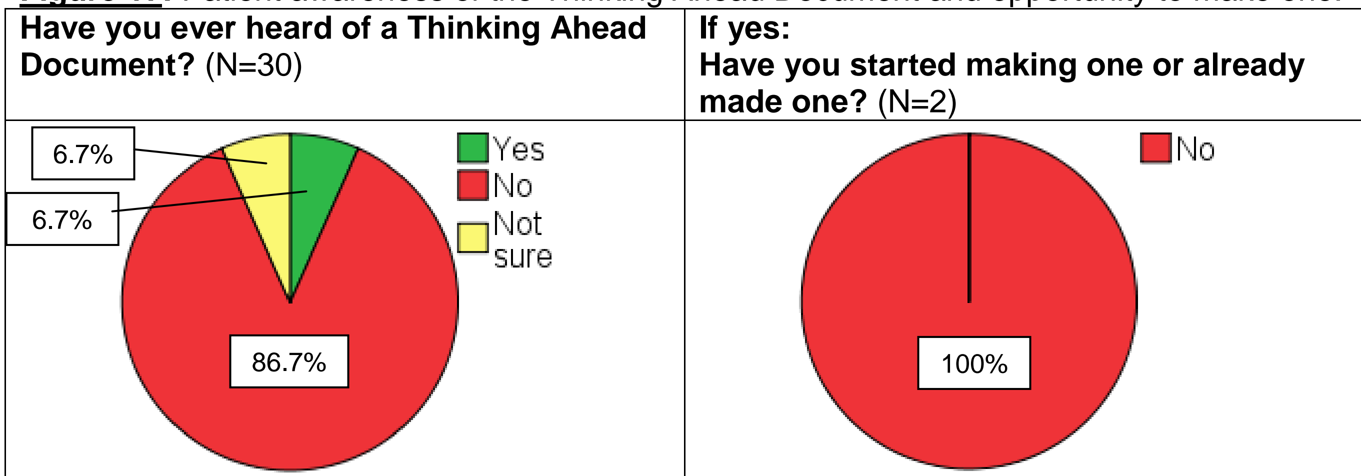
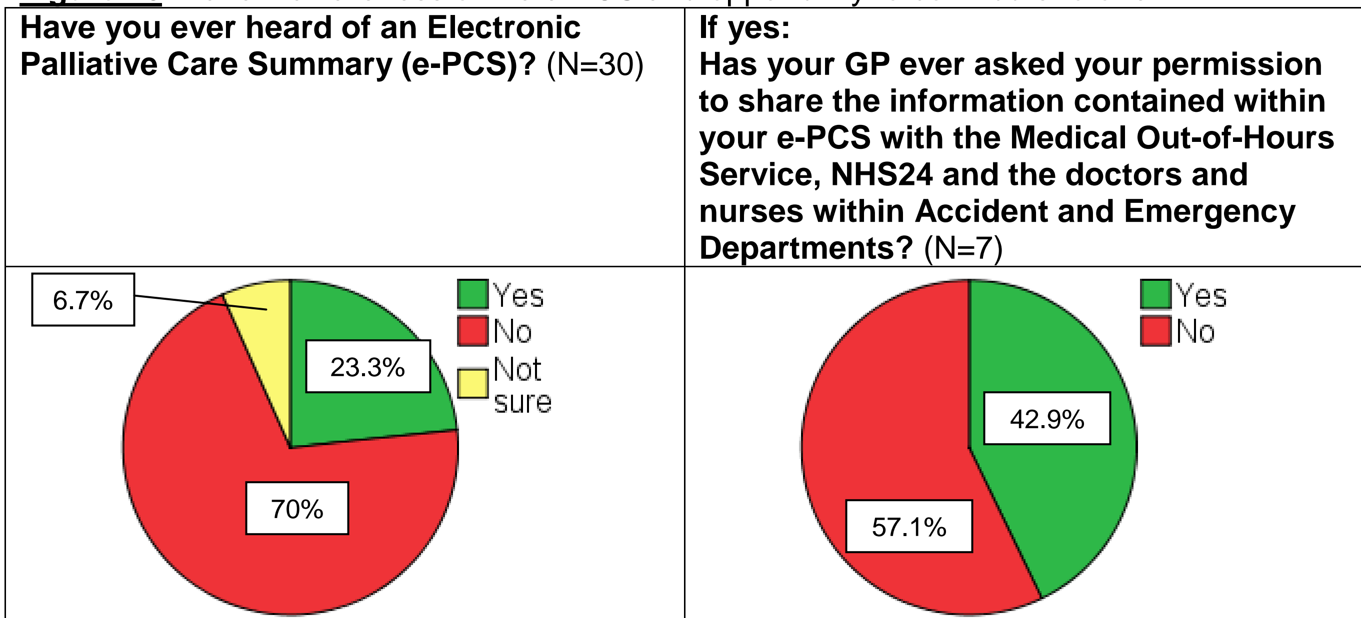


Figure 18: Patient awareness of the e-PCS and opportunity to contribute to one.



Further analysis of the data relating to this Action Point was undertaken using cross-tabulations of Questions 9, 10, and 11 for the patients split into groups based on gender, diagnosis and age. **Tables 15, 16 and 17** present these cross-tabulations.

Table 15: Cross-tabulations by gender, diagnosis and age: patient perception on whether they had ever heard of an Anticipatory Care Plan. No differences worth noting were found between groups for this question.

Gender		
	Female (N=15)	***Male*** (N=15)
Yes	13.3%	20%
No	86.7%	73.3%
Not Sure	0%	6.7%
Diagnosis		
	Cancer (N=20)	***COPD or CHF*** (N=10)
Yes	10%	30%
No	85%	70%
Not Sure	5%	0%
Age		
	49-72 years (N=15)	***73-95 years*** (N=15)
Yes	26.7%	6.7%
No	73.3%	86.7%
Not Sure	0%	6.7%

Table 16: Cross-tabulations by gender, diagnosis and age: patient perception on whether they had ever heard of a Thinking Ahead Document. No differences worth noting were found between groups for this question.

Gender		
	Female (N=15)	***Male*** (N=15)
Yes	6.7%	6.7%
No	93.3%	80%
Not Sure	0%	13.3%
Diagnosis		
	Cancer (N=20)	***COPD or CHF*** (N=10)
Yes	5%	10%
No	90%	80%
Not Sure	5%	10%
Age		
	49-72 years (N=15)	***73-95 years*** (N=15)
Yes	6.7%	6.7%
No	86.7%	86.7%
Not Sure	6.7%	6.7%

Table 17: Cross-tabulations by gender, diagnosis and age: patient perception on whether they had ever heard of an Electronic Palliative Care Summary. No differences worth noting were found between groups for this question.

Gender		
	Female (N=15)	***Male*** (N=15)
Yes	26.7%	20%
No	66.7%	73.3%
Not Sure	6.7%	6.7%
Diagnosis		
	Cancer (N=20)	***COPD or CHF*** (N=10)
Yes	20%	30%
No	80%	50%
Not Sure	0%	20%
Age		
	49-72 years (N=15)	***73-95 years*** (N=15)
Yes	33.3%	13.3%
No	53.3%	86.7%
Not Sure	13.3%	0%

Themes from patient narratives:

The final question of the Questionnaire (Question 15) was not directly assessing one of the aforementioned Action Points. Instead, it was an open-ended question intending to offer patients the opportunity to comment on anything they wished to, relating to their care before or after receiving any services from St Margaret of Scotland Hospice. Out of the 30 patients, 23 decided to offer a comment. Patient comments are presented in **Appendix 7** (page 95). Analysis of these comments identified the following themes which are presented in **Table 18**.

Table 18: Themes identified from comments the patients offered in regards to their experience of the care they received either before or after receiving any services from St Margaret of Scotland Hospice.

Theme 1:	Experience of care before Hospice varied from extremely positive to extremely negative.
Theme 2:	Inadequate communication, insufficient provision of information, not being treated with respect and preservation of dignity, as well as managerial pressure on NHS staff (time, cost cuts, rules, etc.) are related to negative patient experience of their care before the Hospice.
Theme 3:	Service provision by the Beatson West of Scotland Cancer Centre, MacMillan Cancer Support and St Margaret of Scotland Hospice have had a positive impact on patient experience of their care.

Discussion:

Action Point 2:

Action Point 2 recommends patients' palliative needs should be identified and subsequently assessed and reviewed regularly. Based on our results, over 50% of patients were first identified as having palliative needs by either a hospital doctor (33.3%) or their GP (20%). An additional 20% of patients did not know who it was that first identified them as having palliative needs. This finding can have three possible dimensions. Firstly, it may be possible that patients had difficulty understanding the question despite a definition of palliative needs being provided at the beginning of the Questionnaire (see **Appendix 1**, page 61). Secondly, patients might have not been aware of when and by whom they were identified as having palliative needs due to the healthcare professional not explicitly mentioning that the patient had reached that stage in their illness. Thirdly, it might be that these patients were not identified as having palliative needs in a non-specialist palliative care setting either because they indeed did not have any at the time or because their needs were not appreciated.

When asked what was the main issue that had changed for them at the time they were first identified as having palliative needs, 26.7% of patients said that their symptoms or illness had worsened, 20% that they needed more help with everyday activities at home and 13% said that they needed more help managing their symptoms. A further 20% of patients said that they did not know. Once again, this may have been due to confusion related to the question or to lack of a direct discussion between patient and a healthcare professional stating which factors had changed leading to the patient needing extra support.

In regards to assessment of palliative needs, the majority of patients said that they were not asked about how they were coping with their emotional, spiritual and financial needs before coming to the Hospice. In contrast the majority of patients said they were asked about their physical, social and environmental needs. This difference in the assessment of needs might reflect a reluctance of the healthcare staff to enquire about more sensitive issues (emotions, spirituality, finances) compared to more practical aspects (physical, social and environmental needs) of a patient's life and illness. Another potential explanation may be that healthcare staff often use general questions like "How are you today?" instead of explicitly mentioning to the patient which aspect of their needs they are asking about (e.g. "I would like to ask you a few questions about how you feel emotionally"). For physical needs, there was also a difference between the percentage of males and females, with 70% of males saying that they were asked about how they were coping versus 20% of females. It is difficult to say whether this might be related to differences in patient

perception of general questions like “How are you today?” based on gender. For example, females may perceive a general question in a more emotional sense. Another explanation could be that healthcare professionals tend to use a more direct line of questioning with males.

The majority of patients, who said that they had been asked about how they were coping with their palliative needs, said that they had been asked about this regularly enough. Current guidelines[7] recommend assessment every six weeks. Initially, there was a question in the Questionnaire enquiring how often patients’ needs were assessed. When testing the Questionnaire, it became clear that this was confusing for patients since they were unable to remember such detail. Thus, the question was altered to reflect whether the patients felt they were asked regularly enough to help meet their changing needs.

Action Point 4:

Action Point 4 recommends timely, holistic and effective care being available for all patients and being delivered in a person-centred manner.

The majority of the patients said that they felt that their illness was fully explained to them by a healthcare professional in a way they could understand. Still, about one third of the patients who answered this question said their illness was not fully explained to them or they were not sure if their illness was fully explained to them. This is particularly important as patients cannot be expected to get involved in making decisions about their care, as person-centred care indicates, if they are not fully informed about their condition. A number of patients who chose the “not sure” option mentioned that their illness may had been explained to them on their day of diagnosis when they were unable to absorb and retain the information. In addition, there is also the danger of healthcare staff always assuming that someone else has explained the condition to the patient resulting in nobody actually ever explaining. During the interviews certain patients mentioned that they were reluctant to ask questions out of concern that they may be burdening the healthcare staff by wasting their time.

In terms of provision of holistic and effective care, results show that the majority of patients felt they had received sufficient help or advice to meet their holistic palliative needs. However, it is worth noting that for each category of needs, over 25% of patients felt that they had not received enough support. Linking back to the assessment of Action Point 2, the majority of patients had said they had not been asked how they were coping with their emotional, spiritual and financial needs, yet the results for Action Point 4 suggest that the majority of patients felt they had received sufficient help or advice to meet these needs. In order to clarify this controversy, it is worth

mentioning that several patients explained that, even though they were not asked how they were coping, they were managing well on their own, so said they received as much help as they needed even if that meant that they had received no help at all.

Further exploration of the characteristics of patients not receiving enough help is warranted in order for Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland to reach "all patients and families who need it".[1(p.2)] From our preliminary exploration of potentially influential characteristics, it appeared that diagnosis and age influenced how much help people felt they had received to meet their needs. Specifically, a remarkably larger percentage of patients with a diagnosis of cancer felt they had received sufficient help or advice to meet their financial and spiritual needs compared to patients with a diagnosis of COPD or CHF. The difference relating to the financial needs could indicate that there are more resources available for patients with a diagnosis of cancer. In fact, several patients mentioned the positive impact of financial aid provided by MacMillan Cancer Support. The difference relating to spiritual needs may be explained by cancer being perhaps more traditionally regarded as a rapidly progressive, life-limiting illness. Thus, patients with a diagnosis of cancer might receive more spiritual support compared to patients with COPD or CHF. These findings resemble the findings of a study by Murray *et al*[7] which found that, based on patient and carer experience, more health and social care services were available for patients with a diagnosis of cancer compared to patients with a diagnosis of heart failure. It is worth noting that the study by Murray *et al*[8] was published in 2002, thus it is disconcerting that the same situation was echoed by the findings of this audit ten years later.

In relation to the influence of age on patient perception of how much help they had received in order to meet their palliative needs, noticeably more patients in the 73-95 year group said that they had received sufficient help or advice to meet all of their palliative needs compared to the patients in the 49-72 year group. The reason for this finding is unclear. However, based on the narratives from patients during completion of the Questionnaire, we hypothesize that the more elderly patients may demand less from those caring for them. This may be related to some of the more elderly patients perceiving healthcare professionals as experts and trusting they would provide the best for them, thus being reluctant to challenge or question the care they receive. It may also be that some of the more elderly patients view their condition as a natural part of ageing and thus do not have as high expectations from the outcomes of their care. It is worth pointing out that the vast majority of the patients in the 73-95 year group had a diagnosis of cancer. When taking this into account along with the possibility that there are more resources available for the support of patients with a diagnosis of cancer, this could partly explain why more patients in this

group feel that they have received sufficient help to meet their needs. An additional factor may be that available resources are more tailored towards the older patient, perhaps because they are typically thought of as a more vulnerable group. This may leave the younger age group feeling that they are not receiving help in a way that is targeted to their specific needs.

The remaining questions assessing Action Point 4 were designed to assess whether patients felt that their care was delivered in a person-centred manner. When asked about their referral to the Hospice, 20.7% of patients said they were first referred to the Hospice by a hospital doctor. However, an equal percentage of patients did not know who it was that referred them to the Hospice. Despite this, the majority of patients were able to remember someone telling them that they were being referred to the Hospice and explaining why this referral would be beneficial. This is a very encouraging finding, but attention should be drawn to the experiences of those patients who did not know about their referral until they received a hospital letter related to it or until they were contacted by one of the Hospice staff. Even if these are isolated cases, it is important to take measures to avoid such cases given that common misconceptions about hospices and their function can cause serious psychological distress, particularly for patients who have not had a chance to discuss their worries with a healthcare professional.

The final questions asked related to patient perception of their journey throughout non-specialist palliative care as a whole. The majority of patients said that they were treated in a way that was respectful to them as individuals (83.3%), were offered the opportunity to get involved in making decisions about their care (62.5%) and to discuss any worries or concerns (62.5%). Patients with a diagnosis of cancer and those belonging to the older age group replied more positively to some of the above questions about their experience throughout their journey. Potential explanations for this finding are similar to the ones mentioned for the differences observed in the question asking whether patients had received sufficient help or advice to meet their palliative needs. An important factor to consider is that, for many healthcare professionals, respectful treatment, involvement in decision making and opportunity to discuss any arising issues, would be considered the minimum requirements for person-centred patient care. In spite of the majority of the results being positive, it remains important to appreciate that there were still some patients who felt that they did not even receive this minimum level of care. Of course, it is understandable that patients have different expectations for their care and that sometimes one negative experience can influence patients' perceptions of their care as a whole. However, there were patient narratives during this audit that indicated repeated perceived experiences of a poor level of care. Every effort should be made to prevent such cases or to identify and correct them when they arise. As one of

the patients who participated in the audit mentioned, sometimes all it takes to rectify a situation is a sincere apology.

Action Point 10:

Action Point 10 recommends that patients wishing to remain at home should have rapid access to any equipment they need. The percentage of patients who said that the equipment they needed was provided for them by health or social services was very similar to the percentage of patients who said that they already had or had to buy the equipment they needed. Unfortunately, due to the way the second answer option was phrased, it is impossible to distinguish the percentage of people who had to buy the equipment they needed from those that already had it (e.g. from a previous illness of a family member or because they live in sheltered housing). In any case, it is important to note that any equipment that a patient happens to already have, or have had to buy, might not have been properly assessed for appropriateness for this specific patient, thus potentially placing the patient at risk. Of the patients who said their equipment was provided by health or social services, the vast majority said that what they needed was provided quickly enough to meet their needs. This is a particularly positive finding given how important some of these adaptations or equipment can be in maintaining and improving independence and everyday quality of life.

Action Point 16:

Action Point 16 recommends use of effective means of communication among healthcare professionals to enable efficient sharing of patient information and wishes. The results of this audit indicate that patient awareness of ACP, Thinking Ahead and e-PCS was poor. The vast majority of patients had never heard of these documents. Of those who had heard of one of these documents, less than 50% had or had started making one. Although the decision to have one of these documents rests with the patient, the responsibility for increasing patient awareness of such documents' existence and their potential usefulness rests with the healthcare professionals. There is a possibility that patients answering this question might have been unfamiliar with the terms used for these documents even though their healthcare team may have described these documents to them in the past. Every effort was taken to minimize this problem by providing a short description of the purpose of each of these documents in the Questionnaire. During data collection, some patients mentioned that they had difficulty seeing the same GP every time and complained that this had a negative impact on their ability to form and maintain a trusting relationship with the GP. A

hypothesis may be that this can also have an impact on the GPs who may not feel comfortable breaching sensitive issues, such as those surrounding the palliative care documents, with patients who they do not feel they have a deep relationship with. Finally, it is worth noting that, upon completion of the Questionnaire, 6 out of 11 patients who asked to be contacted by one of the Hospice clinicians to discuss any questions or concerns that arose after taking part in the audit, wished to discuss the possibility of creating one of these documents.

Strengths of the present audit:

- To our knowledge, this is the first audit which has assessed patient perception of non-specialist palliative care in relation to Living and Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland
- This audit included both patients with a diagnosis of a malignant condition and patients with a non-malignant condition.
- This audit included patients both from the Edwina Bradley Day Hospice and from the community.
- The questions and answer options in the Questionnaire were based on themes that had emerged from patient focus groups.
- The Questionnaire was tested and adjusted based on expert and patient feedback. The Questionnaire was also checked for appropriateness of level of language.
- The audit coordinators read the questions to patients and marked the answers each patient chose. This provided an opportunity for the patients to explain the reasons behind why they chose each answer. Even though these conversations were not formally recorded and analysed, they allowed better insight into how the results of this audit might be better explained. The same applies to the importance of the inclusion of an open-ended question at the end of the Questionnaire.
- Neither of the audit coordinators were employed by the Hospice. Additionally, the audit itself was not assessing provision of services by the Hospice. This should have made it less likely for patients to have felt pressured into choosing specific responses.

Weaknesses of the present audit:

- The questions in the Questionnaire asked patients to recall their care before coming to the Hospice. For some patients this might have been several months ago and at a time that they were very unwell. This could have introduced recall bias into the data.

- This audit assessed patient perception of the care they had received. This may or may not be a direct reflection of the actual care they received. However, assessing patient perception was imperative, given that the way patients experience their care is of great importance.
- The Action Points within Living and Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland were written in broad terms. Consequently, it is difficult to know whether the questions in the Questionnaire assessed the entire breadth of each action point.
- Given that the patient sample for this audit was small and was selected from patients of one Hospice, it is difficult to generalise any findings to the whole population of people who have received non-specialist palliative care services since Living and Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland first came into action.
- In an attempt to respect the vulnerability of patients in a more fragile physical or emotional state, these patients were excluded from participating in the present audit. There is uncertainty as to whether this may have influenced the results.
- Due to the relatively small sample size of this audit, it was not possible to analyse the statistical significance of differences in responses between groups of patients based on diagnosis, gender or age.

Conclusion:

This audit demonstrated that patient experience of their care prior to receiving any of the Hospice services ranged from extremely positive to extremely negative. Several findings of this audit were encouraging and showcased positive patient experiences which may be closely related to the successful implementation of Living and Dying Well. These include adequate assessment of physical, social and environmental needs, quick provision of needed adaptations or equipment and sufficient provision of patient-centred care for the majority of patients. Conversely, assessment of emotional, spiritual and financial needs was poor as was the information provided to patients regarding ACP, Thinking-Ahead and e-PCS. Overall, even within these findings for which the majority had positive experiences, there was a noticeable percentage of patients who felt that they were not provided with even the minimum level of care expected. These discrepancies lead us to question whether Living and Dying Well has indeed achieved its aim of improving palliative care for all who require it.[1] This current audit can be perceived as a pilot audit for a more comprehensive representative further audit, which is essential to assess the implementation and application of Living and Dying Well.

Recommendations:

Clinical Practice:

- There should be a direct discussion between the healthcare professional and the patient when the patient is identified as having palliative needs. The discussion should make clear what the implication of being identified as having palliative needs is for the patient's life and illness.
- When assessing patient needs, healthcare professionals should use specific questions so that each of the holistic needs can be assessed separately and in a systematic manner.
- Each healthcare professional should take responsibility for assessing the extent of each patient's knowledge regarding his/her illness and identify patient preferences in regards to how much information the patient wishes to know about his/her illness. Healthcare professionals should ensure the patient is provided with information, if it is required, and record any discussion in the patient's notes.
- Healthcare professionals should be made more aware that elderly patients may be reluctant to ask questions and may need more encouragement in order to better express their needs and wishes.
- More effort should be given to tailoring non-specialist and specialist palliative care services towards age-specific needs, and in particular towards the needs of the younger age groups.
- Healthcare professionals should be made more aware that patients with COPD and CHF may be more vulnerable due to less illness-specific support services being available. Timely and thorough assessment of patient needs in this population of patients may therefore be even more important in order to ensure that their patients receive all the help they need.
- All patients should be informed of their referral to specialist palliative care services and the reasons for this referral. Patient understanding of this discussion should be assessed and the discussion recorded in the patient's notes.
- Members of the healthcare team should regularly assess patient satisfaction with their care using specific questions assessing patient involvement in their care and patient concerns about their care. In response to patient answers, appropriate action should be taken to rectify any issues that may have arisen.
- Healthcare professionals should increase awareness of documents such as APC, Thinking Ahead and e-PCS. Every patient should be offered the opportunity to have the aforementioned documents when they are identified as having palliative needs. Subsequent

opportunities should be offered as the patient's condition progresses or when a patient is referred for specialist palliative care.

Education:

- Efforts should be made to increase public awareness of the right to a good death. The public should be offered more information on what this means and how it can be achieved. This recommendation is partly being fulfilled by the on-going work of the Scottish Partnership for Palliative Care (SPPC) through the Good Life, Good Death, Good Grief project.[9]
- Communication skills training for students and professionals in healthcare should incorporate more extensive teaching on breaching the sensitive issues surrounding palliative care with patients. This should include issues such as holistic assessment of the patient, appreciation of the patient's thoughts and feelings and of their preferred place of care and death as well as anticipatory care planning.
- Further training may be needed to increase healthcare professional knowledge about ACP, Thinking Ahead and e-PCS and their usefulness for staff, patients and families.

Research:

- Research is necessary to establish the specific characteristics of the patients who do not feel they receive sufficient help to meet their needs, in the hope that this will assist in better identification of these patients in clinical practice.
- Research is necessary to investigate the quality of care provision in each of the primary, secondary and tertiary care setting as well as to how this is related to patient perception of and satisfaction with the care they received.
- Research is necessary to investigate patient perception of care provision through thematic analysis of structured interviews in an attempt to better understand patient attitudes and expectations with respect to palliative and end of life care.

Action Plan:

- Results of the present audit will be distributed to all relevant authorities including the following:
    - Scottish Government
        - Health and Sport Committee
        - Cabinet Secretary for Health and Wellbeing
    - Chief Scientist Office
    - National Clinical Lead for Living and Dying Well
    - NHS Greater Glasgow and Clyde Palliative Care Managed Care Network (MCN)
    - National Advisory Group for Living and Dying Well
    - Health Improvement Scotland
    - Scottish Partnership for Palliative Care (SPPC)
    - NHS Education for Scotland
    - NHS Greater Glasgow and Clyde Hospices and Hospice Educators
    - NHS Greater Glasgow and Clyde Palliative Care Website Editorial Group
    - Glasgow City Community Health Partnerships - West
    - East and West Dunbartonshire Community Health Partnerships
- Appropriate alterations will be made to the Hospice education programme in order to incorporate the recommendations based on this audit.
- Appropriate alterations will be made to the Hospice admission process in order to incorporate the recommendations based on this audit. The intent will be to increase the information collected at the initial point of contact with each patient in order to identify whether all palliative needs are being met, whether the patient has enough information about their illness, whether the patient has any questions, and to introduce the concepts of ACP, Thinking Ahead and e-PCS to the patient.

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Appendix 1
Questionnaire

Audit of Patient Experience about the Implementation of Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland

Age:

Gender:

Illness or Diagnosis:

Aim of the audit:

The aim of this audit is to determine if, from personal experience, the following action points taken from Living & Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland have been implemented. This action plan was circulated to all NHS Boards in October 2008.

Action 2:

NHS Boards should ensure that patients identified with palliative needs and/or end of life care needs are appropriately assessed and reviewed in all care settings using recognised tools currently available.

Action 4:

Services in each NHS Board area should work together to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person centered and responsive to the needs and diversity of the population at appropriate stages of the patient journey.

Action 10:

NHS Boards should ensure that rapid access is available to appropriate equipment required for the care of those wishing to be at home or die at home from any advanced progressive illness.

Action 16:

NHS Boards should ensure that safe and effective processes, electronic or otherwise, are in place 24/7 to enable the transfer or sharing of important information specific to the person’s illness, as identified in the electronic Palliative Care Summary (e-PCS) and where consent has been given.

The way in which you respond to this questionnaire will help to identify whether the action points have made any difference to the care you have received.

In order to answer the following questions, it would be helpful for you to know what palliative care means and this explanation may help you:

Unfortunately, some illnesses are long term, will get worse over time, and cannot be cured. Examples of these illnesses are heart disease, chronic obstructive pulmonary disease (COPD), cancer and neurological conditions such as motor neuron disease (MND). These illnesses may mean that people need more help from social services (such as home helps), nurses, doctors and relatives or even neighbours and friends. People may be attending hospital frequently or may require admission more often. These people may benefit from **palliative care**.

Palliative care is a supportive approach focusing on needs which may be emotional, physical, social, environmental, or spiritual. Getting help to meet these needs may make the person feel better. We refer to these needs in the questionnaire as **palliative needs**.

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Your illness:

Assessing Action Point 4

1. Do you feel that your illness was fully explained to you by a healthcare professional in a way that you could understand?

Please tick:

Yes □ **No** □ **I am not sure** □

If you have marked 'Yes':

1a. Who was it that first explained your illness to you in a way which you could understand?

Please tick (choose only one):

My GP □

Hospital Doctor □

Community MacMillan Nurse □

Respiratory Nurse □

Heart Failure Nurse □

Hospital Palliative Care Nurse or MacMillan Nurse □

Other (please write) … □

I Don't Know □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Assessing Action Point 2

Your palliative needs:

2. After you were diagnosed with a progressive and life-limiting illness, who first identified you as having palliative needs?

Please tick (choose only one):

My GP ☐

Hospital Doctor ☐

Community MacMillan Nurse ☐

Respiratory Nurse ☐

Heart Failure Nurse ☐

Hospital Palliative Care Nurse or MacMillan Nurse ☐

Other (please write) … ☐

I Don't Know ☐

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Assessing Action Point 2

Your palliative needs (continued):

3. What was the main thing that had changed for you at the time you were identified as having palliative needs?

Please tick (choose only one):

My symptoms or illness worsened □

I needed more help managing my symptoms □

I needed more emotional support □

I needed more support with finances □

I needed more support with everyday activities at home □

My family needed more support caring for me □

Other (please write) … □

I don't know □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Assessment:

Assessing Action Point 2

4. Before coming to the Hospice, had someone asked how you were coping with the following needs?

Please tick (choose only one for each):

- **Physical Needs** – is about your illness and physical symptoms, such as pain, nausea, constipation, loss of appetite, loss of weight

  Yes □ **No** □ **I am not sure** □

- **Emotional Needs** – is about how you feel about what is wrong with you and how you are coping

  Yes □ **No** □ **I am not sure** □

- **Social Needs** – is about help with everyday tasks at home (e.g. toileting, bathing, dressing, eating, taking medication, shopping, cleaning)

  Yes □ **No** □ **I am not sure** □

- **Environmental Needs** – is about your house and environment, changes to your independence or how you manage at home (aids, adaptations or equipment)

  Yes □ **No** □ **I am not sure** □

- **Spiritual Needs** – is about how you feel about yourself, what life means to you, what is important to you in your life and faith

  Yes □ **No** □ **I am not sure** □

- **Financial Needs** – is about changes to your income, benefits you may be entitled to or any financial difficulties experienced due to your illness

  Yes □ **No** □ **I am not sure** □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

If you have answered yes to any part of question 4:

4a. Do you feel that you were asked regularly enough about how you were coping with the following needs?

Please tick (choose only one for each):

- **Physical Needs** – is about your illness and physical symptoms, such as pain, nausea, constipation, loss of appetite, loss of weight

  Yes □ **No** □ **I am not sure** □

- **Emotional Needs** – is about how you feel about what is wrong with you and how you are coping

  Yes □ **No** □ **I am not sure** □

- **Social Needs** – is about help with everyday tasks at home (e.g. toileting, bathing, dressing, eating, taking medication, shopping, cleaning)

  Yes □ **No** □ **I am not sure** □

- **Environmental Needs** – is about your house and environment, changes to your independence or how you manage at home (aids, adaptations or equipment)

  Yes □ **No** □ **I am not sure** □

- **Spiritual Needs** – is about how you feel about yourself, what life means to you, what is important to you in your life and faith

  Yes □ **No** □ **I am not sure** □

- **Financial Needs** – is about changes to your income, benefits you may be entitled to or any financial difficulties experienced due to your illness

  Yes □ **No** □ **I am not sure** □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Help and Support:

Assessing Action Point 4

5. Have you received sufficient help or advice to meet your palliative needs?

Please tick (choose only one for each):

- **Physical Needs** – is about your illness and physical symptoms, such as pain, nausea, constipation, loss of appetite, loss of weight

  Yes □ **No** □ **I am not sure** □

- **Emotional Needs** – is about how you feel about what is wrong with you and how you are coping

  Yes □ **No** □ **I am not sure** □

- **Social Needs** – is about help with everyday tasks at home (e.g. toileting, bathing, dressing, eating, taking medication, shopping, cleaning)

  Yes □ **No** □ **I am not sure** □

- **Environmental Needs** – is about your house and environment, changes to your independence or how you manage at home (aids, adaptations or equipment)

  Yes □ **No** □ **I am not sure** □

- **Spiritual Needs** – is about how you feel about yourself, what life means to you, what is important to you in your life and faith

  Yes □ **No** □ **I am not sure** □

- **Financial Needs** – is about changes to your income, benefits you may be entitled to or any financial difficulties experienced due to your illness

  Yes □ **No** □ **I am not sure** □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Help and Support (continued):

Assessing Action Point 10

6. Since you were diagnosed with a progressive illness have you needed any adaptations or equipment to help you stay at home?

Yes □ **No** □

If yes:

6a. How did you get each of the adaptations or equipment that you needed? (i.e. did you or your family have to pay or was it provided for you by social or healthcare services).

Please tick (choose only one for each):

	I did not need this	**My family or I had it or had to buy it**	**It was provided for me**	**Some I had or had to buy, some were provided**	**I needed this but it was not provided**
Walking aids (e.g. walking stick, zimmer frame, wheeled frame, crutches)					
Mobility aids (e.g. scooter, manual wheelchair, electric wheelchair)					
Aids to help you get in your home (e.g. ramp, stair climber, grab rails)					
Toileting aids (e.g. special toilet seats or frame, grab rails, commodes)					
Bathing aids (e.g. electrical bath lift, shower or bath seat)					
Bedroom aids (e.g. grab rails, mattress elevator, hospital bed)					
Kitchen aids (e.g. trolley, perching stool)					
Living room aids (e.g. riser/recliner chair)					
Adaptations to your home (e.g. walk-in shower, stair lift, house extension, Intercom system)					
Other (please write)…					

This questionnaire is about your life and illness **BEFORE** having any of the Hospice services.

If any adaptations or equipment were provided for you by the social or healthcare services:

6b. Which do you feel were provided quickly enough to meet your needs?

Please tick (choose only one for each):

	Were provided quickly enough	**Were not provided quickly enough**	**Some were provided quickly enough, some were not**
Walking aids (e.g. walking stick, zimmer frame, wheeled frame, crutches)			
Mobility aids (e.g. scooter, manual wheelchair, electric wheelchair)			
Aids to help you get in your home (e.g. ramp, stair climber, grab rails)			
Toileting aids (e.g. special toilet seats or frame, grab rails, commodes)			
Bathing aids (e.g. electrical bath lift, shower or bath seat)			
Bedroom aids (e.g. grab rails, mattress elevator, hospital bed)			
Kitchen aids (e.g. trolley, perching stool)			
Living room aids (e.g. riser/recliner chair)			
Adaptations to your home (e.g. walk-in shower, stair lift, house extension, Intercom system)			
Other (please write)…			

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Help and Support (continued):

Assessing Action Point 4

7. Who first referred you to St. Margaret of Scotland Hospice?

Please tick (choose only one):

My GP □

Hospital Doctor □

Community MacMillan Nurse □

Respiratory Nurse □

Heart Failure Nurse □

Hospital Palliative Care Nurse or MacMillan Nurse □

Other (please write) … □

I Don't Know □

8. Do you remember being told about your referral to the hospice?

Yes □ **No** □ **I am not sure** □

If yes:

8a. Do you remember the person who referred you explaining why they thought you would benefit from referral to the hospice?

Yes □ **No** □ **I am not sure** □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Communicating Important Information about your Illness:

Assessing Action Point 16

Anticipatory Care Plan (ACP) – is a plan created by the **clinical team** (doctors and nurses) responsible for your care following assessment of your illness and relates to how you should be cared for in the future

9. Have you heard of an Anticipatory Care Plan (commonly known as ACP)?

Yes □ **No** □ **I am not sure** □

If yes:

9a. Have you started making or already made one?

Yes □ **No** □ **I am not sure** □

Thinking Ahead – is a plan created by **you or your family** and relates to your wishes or preferences of how you wish to be cared for in the future

10. Have you heard of a Thinking Ahead Document?

Yes □ **No** □ **I am not sure** □

If yes:

10a. Have you started making or already made one?

Yes □ **No** □ **I am not sure** □

Electronic Palliative Care Summary (e-PCS) – is an electronic document which is updated by your GP and records information specific to how you should be cared for in an emergency situation. This information would be read by the Medical Out-of-Hours Service, NHS24 and the doctors and nurses within Accident & Emergency departments

11. Have you heard of an Electronic Palliative Care Summary (e-PCS)?

Yes □ **No** □ **I am not sure** □

If yes:

11a. Has your GP ever asked your permission to share the information contained within your e-PCS with the Medical Out-of-Hours Service, NHS24 and the Doctors and Nurses within Accident & Emergency departments?

Yes □ **No** □ **I am not sure** □

This questionnaire is about your life and illness BEFORE having any of the Hospice services.

Assessing Action Point 4

Your Journey and Experience:

12. Overall, do you feel that throughout your journey, treatment has been offered in a way that has been respectful of you as an individual?

Please tick:

Yes □ **No** □ **I am not sure** □

13. Overall, do you feel that throughout your journey, you have been offered the opportunity to get involved in making decisions about your care?

Please tick:

Yes □ **No** □ **I am not sure** □

14. Overall, do you feel that throughout your journey, you have had the opportunity to discuss any concerns or worries you may have about your care?

Please tick:

Yes □ **No** □ **I am not sure** □

15. Is there anything else you would like us to know or would like to share with us:

Thank you for taking time to complete this questionnaire.

If completing this questionnaire has raised any concerns or thoughts about your illness that you would like to discuss, and you would like one of the Senior Clinical Team members to contact you, please tick this box ☐

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Appendix 2
Patient Information Leaflet

Information Leaflet:

Audit of Patient Experience about the

Implementation of Living and Dying Well –

A National Action Plan for Palliative and End of Life Care in Scotland

We would like to invite you to take part in an audit.

Before you decide if you want to participate it is important for you:

To understand why this audit is being done

To understand what it will involve

Please take time to read the following information carefully. Please ask us if there is anything that is not clear or if you would like more information.

Take your time to decide whether or not you wish to take part. You can choose not to take part if you do not want to and your decision will not change how we care for you.

What is the purpose of the audit?

All healthcare organizations need to carry out **audits**. An audit looks into whether all procedures are carried out according to existing recommendations. This should help make sure that patient care is the best possible.

When a person has an illness, which is unfortunately long term and over time will get worse, and which cannot be cured, they may need **palliative care**. Examples of these illnesses are heart disease, chronic obstructive pulmonary disease (COPD), cancer and neurological conditions such as motor neuron disease (MND).

The illness may mean that a person needs more help from social services (such as home helps), nurses, doctors and relatives or even neighbours and friends. They may often be attending hospital or may need to be admitted to hospital more often. **Palliative care** is a supportive approach focusing on needs which may be emotional, physical, social, environmental, or spiritual. Getting help to meet these needs may make the person feel better.

The Scottish Government has set up recommendations for palliative care called Living and Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland. **With this audit we are trying to identify whether people feel that these recommendations have helped them during their illness.** Specifically, we are looking at how:

Palliative needs are identified

Care is planned

Important information about a person's illness is shared with all others involved in that person's care

Why have I been chosen?

We are asking you to participate in this audit because you are currently coming to the Edwina Bradley Day Hospice or because you are being supported at home by one of the Hospice Community Nurse Specialists and because your illness started causing you more problems during or after 2009.

Do I have to take part?

No. It is up to you to decide whether or not to take part in this audit. If you do decide to take part we will give you an information sheet to keep and ask you to sign a consent form.

If you decide to take part you can stop at any time and you do not have to give a reason.

If you choose not to take part in this audit, your decision will not change how we care for you.

What will I have to do if I take part?

If you decide to take part in this audit, we will ask you to sign a consent form and complete a questionnaire.

We will give you two copies of a consent form to sign. You can keep one of the copies for yourself and the other will remain attached to the questionnaire.

We will then ask you to complete the audit questionnaire. This will include questions about palliative care and your experience of this **before coming to the Hospice**. The questionnaire will take about 20 minutes to complete. One of the audit coordinators will be available if you need help with completing the questionnaire.

After finishing, you will return the questionnaire to the audit coordinator.

Day Hospice **-** If you usually come to the Day Hospice, one of the audit coordinators will join you during your time at the Day Hospice to give you the questionnaire to complete. If possible, we will offer you a private space in which to complete the questionnaire.

Hospice Services at Home **-** If you usually receive hospice services at home, your Community Nurse Specialist will ask you whether you are interested in participating. If you say yes, they will ask your permission for one of the audit coordinators to phone you to arrange a time to visit you at home in order to complete the questionnaire.

What are the possible disadvantages and risks of taking part?

You may find some of the questions within the questionnaire upsetting as they relate to you as a person and your illness. You do not need to answer any of the questions that you do not want to answer.

If, after completing the questionnaire you have any concerns or questions about your illness or care, please tick the box at the end of the questionnaire. One of the hospice doctors will get in touch with you to discuss your concerns or questions.

What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this audit. We hope that the information we collect during this audit will give us a better understanding of palliative care services outside of the hospice and may help improve these services in the future.

Will my taking part in this audit be kept confidential?

All information which we collect about you during the course of the audit will be kept strictly confidential. We will ask you to complete your name and date of birth on the consent form for the audit but this information will not be connected to your answers within the questionnaire. Instead, we will give your questionnaire a unique identification number which we will keep it separately from your consent form.

The only occasion in which your identity will be linked to the questionnaire will be if you tick the box in the questionnaire indicating that you wish to be contacted by one of the hospice doctors to discuss any concerns or questions. In this case, we will only share information identifying you with the hospice doctor.

As part of the consent form for this audit we will also ask you to give us the name of your GP (General Practitioner) and the name of the practice or medical centre. We will also ask you for permission to contact your GP and let them know that you are taking part in this audit. The reason we ask for this information is to make sure that your GP knows about the audit and that you have decided to participate as your GP still has the overall responsibility for your care. This will also make it easier for you to speak to your GP if completing the audit questionnaire brings up any questions or concerns that you wish to discuss with someone outside of the hospice. Your GP will receive a general letter saying that you have agreed to participate in this audit but they will not see any of your answers to the audit questionnaire. This way, your answers will remain confidential.

What will happen to the findings of the audit?

The findings of the audit will form a report and presentation for professionals in palliative care and those responsible for planning palliative care services or educating health and social care professionals.

If you wish to see a copy of the results of this audit, please give us a contact address when you sign the consent form. We will then post a summary of the audit results to you when the audit is completed (after September 2012).

Who is organising and funding the audit?

The audit is organized by St. Margaret of Scotland Hospice. As part of the audit team, two medical students (audit coordinators) were funded by the University of Glasgow Settlement.

Who has reviewed this audit?

The protocol and all documents related to this audit have been reviewed by all the audit team members and approved by the Hospice Executive. This audit has been reviewed by the Hospice Clinical Governance Team.

For further information please contact:

Professor John Welsh; Hospice Consultant in Palliative Medicine

Elizabeth Thomas; Director of Clinical Services

Jacquie Lindsay; Hospice Lecturer

All of the above staff may be contacted via the main switchboard of the hospice on 0141 952 1141.

Thank you for taking the time to read this information leaflet.

We will give you a copy of this information leaflet and the consent form for you to keep.

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East Barns Street, Clydebank, G81 1EG

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Email: office@smh.org.uk

Telephone: 0141 952 1141

Fax: 0141 951 4206

Appendix 3
Consent Form

Audit of Patient Experience about the Implementation of Living and Dying Well –
A National Action Plan for Palliative and End of Life Care in Scotland

Consent Form

Audit Coordinators:
Jennifer Mitchell Medical Student
Elpida Papadantonaki Medical Student

	Please initial box
I confirm that I have read and understand the information sheet dated 17/07/2012 for the above audit.	
I have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights or care being affected.	
I understand that information within this questionnaire will be confidential and I will remain anonymous unless I choose otherwise.	
I understand that my GP (General Practitioner) will be notified about my decision to participate in this audit but will not be given access to my answers within the questionnaire.	
I agree to take part in the above audit.	

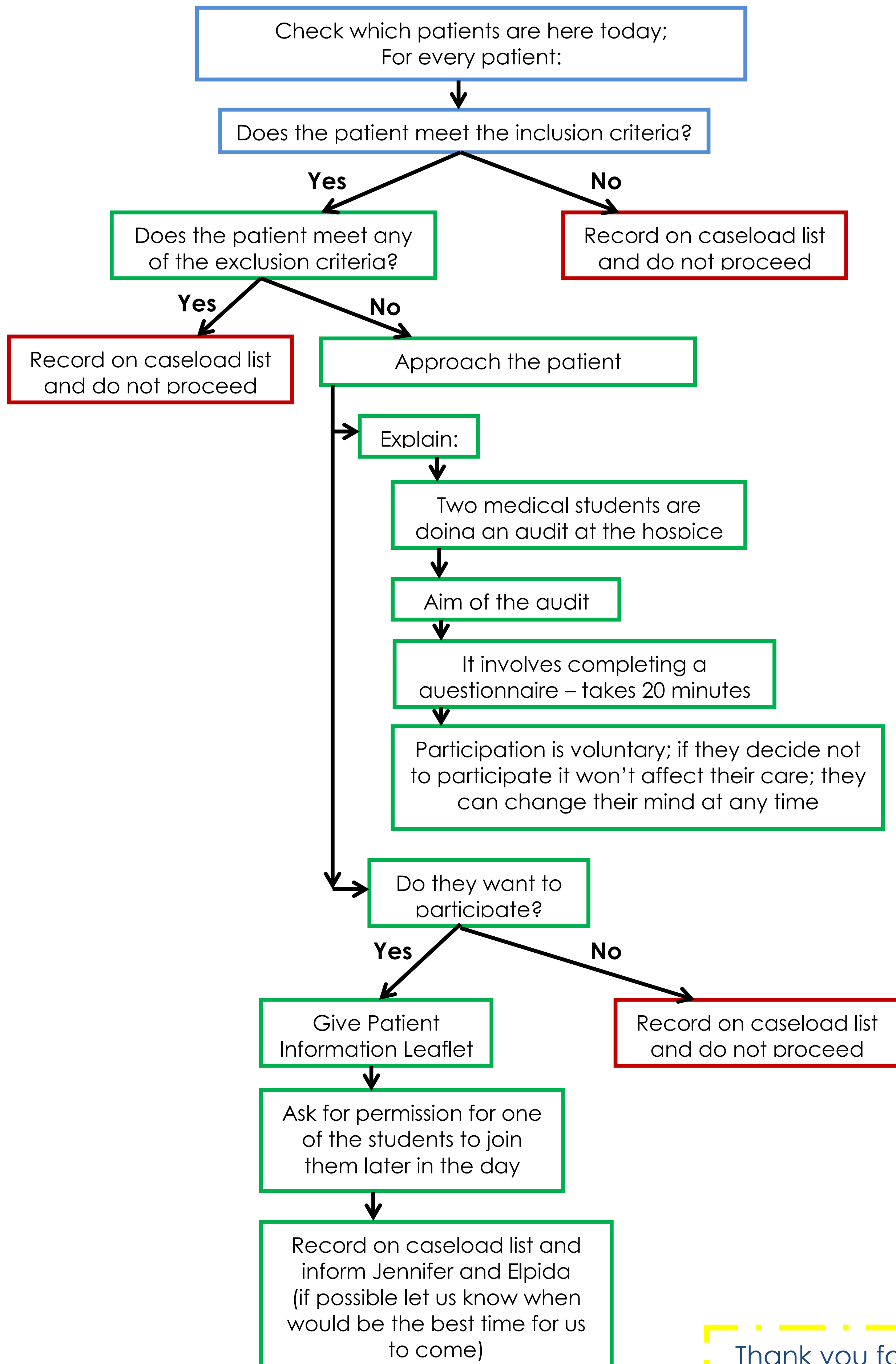
Participant Information:
Name: ____
Date of Birth: ____
GP name: ____
GP practice name and area (address, or post code): ______________________
____

Name of participant Date Signature
________________________ ___________ ________________

Name of Person taking consent Date Signature
________________________ ___________ ________________

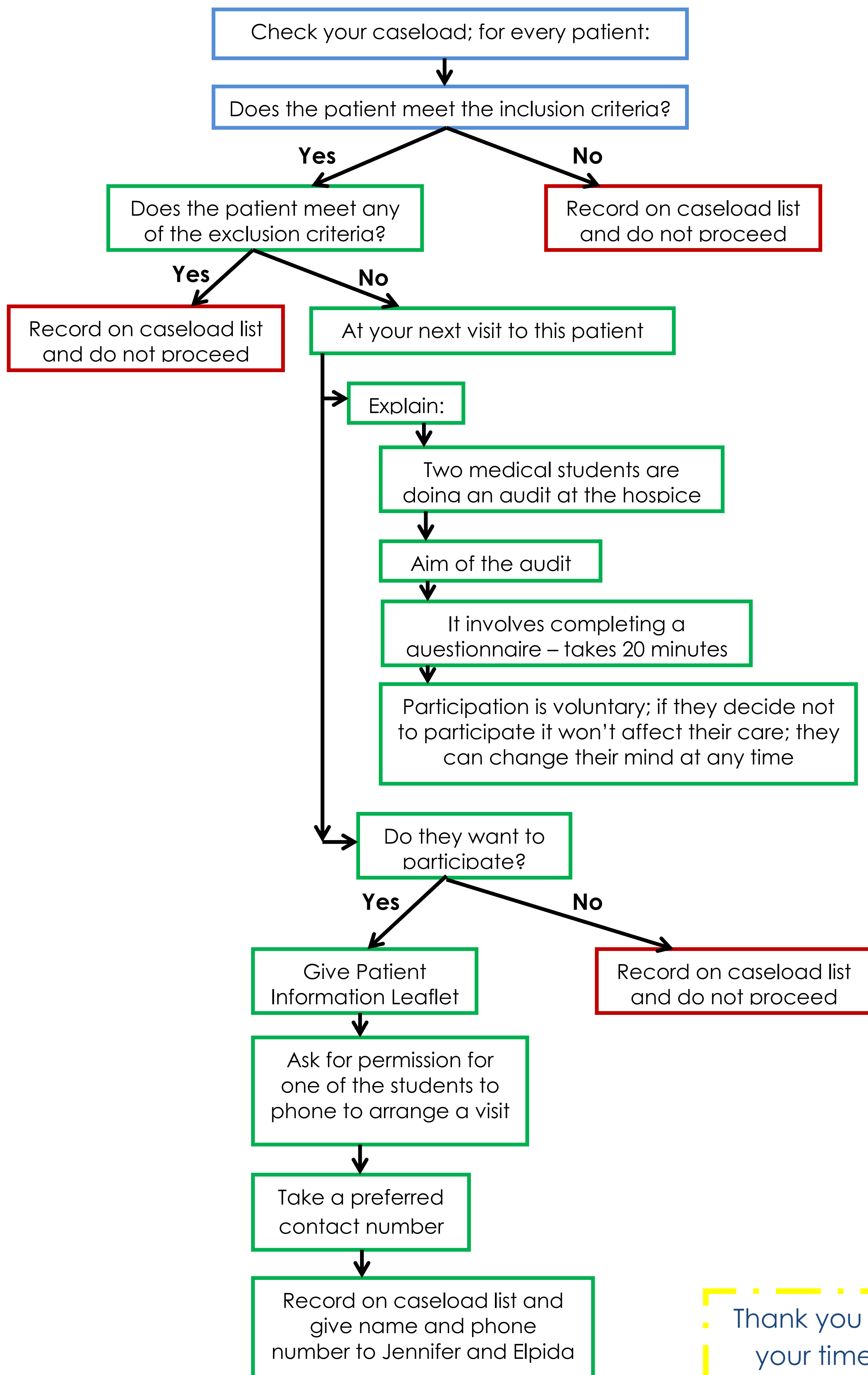
If you wish to receive a copy of the results of this audit please provide us with a contact address below:
____
____

Appendix 4
Flowchart for Edwina Bradley Day Hospice staff



Thank you for your time!

Appendix 5
Flowchart for Community Specialist Palliative Care Team


Check your caseload; for every patient:
Does the patient meet the inclusion criteria?
Yes
No
Does the patient meet any of the exclusion criteria?
Record on caseload list and do not proceed
Yes
No
Record on caseload list and do not proceed
At your next visit to this patient
Explain:
Two medical students are doing an audit at the hospice
Aim of the audit
It involves completing a questionnaire – takes 20 minutes
Participation is voluntary; if they decide not to participate it won't affect their care; they can change their mind at any time
Do they want to participate?
Yes
No
Give Patient Information Leaflet
Record on caseload list and do not proceed
Ask for permission for one of the students to phone to arrange a visit
Take a preferred contact number
Record on caseload list and give name and phone number to Jennifer and Elpida
Thank you for your time!

Appendix 6
Letter sent to participants' GPs

St. Margaret of Scotland Hospice
East Barns Street, Clydebank
Dunbartonshire, G81 1EG
Tel: 0141 952 1141 Fax: 0141 951 4206
Website: www.smh.org.uk *E-mail*: office@smh.org.uk

Sister Rita Dawson, RSC DL BSc(Hons) MSc RGN RSCN
Chief Executive

Professor Leo Martin, LLB (Hons) Dip.LP NP
Chairman

Dr

Re: Audit Participation

/0/2012

Dear Dr …,

We are writing to inform you that one of your patients, Mr/Mrs/Ms…. (dob), has agreed to participate in an audit at St. Margaret of Scotland Hospice.

The audit title is "Audit of Patient Experience about the Implementation of Living & Dying Well - A National Action Plan for Palliative and End of Life Care in Scotland". The audit involves the patient completing a questionnaire about their overall experience of palliative care before referral to St. Margaret of Scotland Hospice, in relation to Action Points 2, 4, 10 and 16 of the aforementioned document.

As part of the questionnaire patients are given the opportunity to ask for one of the hospice clinicians to contact them in order to discuss any questions or concerns relating to their illness. We understand that the topic underpinning the audit is sensitive, so we want to make sure that you are informed just in case the patient chooses to contact you instead of, or in addition to, the hospice clinician. The patient has consented to you knowing about their participation.

You would be welcome to contact us if you require any additional information or wish to discuss the audit in more detail.

Yours sincerely,

Elizabeth Thomas
Director of Clinical Services

Dr B.O. Williams, Vice President
Patrons: His Grace Archbishop Mario Conti, KC* HS PhL STL DD FRSE
Professor the Baroness Finlay of Llandaff FRCP FRGCP, Lady Hamill, Sir Kenneth Calman KCB MD FRCS FRCE
Mrs B.O. Williams, Mr Johnny Beattie, Mr Peter Martin
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Appendix 7
Patient narratives offered as answers to Question 15

- “The whole profession and general public should be educated about COPD. Receptionists need a good boot up the arse. They treat everyone the same. The way I am treated hurts. I think health and safety has gone too far” (with respect to staff handling samples of e.g. sputum). “I feel I would get better treatment in prison. I am a house prisoner” (with respect to housing department). “We are all human beings. I just want to be treated with dignity.”

- “It was difficult. Things are different now. This place has made a big difference to my life. And the MacMillan Nurse has made a big difference.”

- “I cannot speak highly enough about the staff in the Beatson; from the consultants to the cleaners. They are amazing. They work so hard.”

- “I do have an APC but the staff were unable to access it at the Western. A & E and two wards took copies of my individual copy of ACP. There should be more info available about it. Not enough people know” (mentioned that the ambulance crew hadn't seen one before). “I feel everyone should have one. I've seen how helpful it can be. It does work if it's used properly.”

- “The experience of coming here has been great for me. I've only been coming here for a week and I'm a changed person. If there was any way of telling all patients that this is available… don't miss it if you need it.”

- “A lot went wrong with my history. I was overdosed on chemo and it was started too early. I would have liked more in depth tests for my heart problems instead of just chats. I think that the staff are doing as little as possible in terms of testing people due to the NHS cuts. There is a lot of neglect, but not intentional neglect, due to the NHS cuts.” “I was in the tunnel but I couldn't see the light.” (talking about care before the Hospice)

- “Nurses are not too bad but some of the hospital doctors have attitude problems. I would have appreciated more input from the respiratory nurses.”

- “I think I have been extremely well looked after. I don't have any complaints for the doctors or the hospitals. You need a family to help you along though.”

- “I think I get well looked after. My daughter helps out as well.”

- “I am quite happy with the hospice. It is with home that I will have to get things sorted.”

- “Everything was so unexpected. I just had to take it as it comes” (talking about living with an illness). “Nobody really explained the ins and outs of it to me. I was just given a name”. (Remembers receiving a letter after discharge from the hospital mentioning a referral for palliative care at St Margaret's Hospice) “I thought this meant that I was going there to die...I remember sitting there all night looking at the paper and crying”.

- “Whilst I will not offer any criticism about how care is dispensed…no great criticism of the quality of care…a wee bit of criticism about [home care company name]. They are, in many respects, excellent but they are negligent about telling you who they are going to send and when. It is not right that you don't know who comes to your door. Their organisation is horribly bad.”

- “No complaints.”

- “Everything has been alright.”

- “I would like doctors and nurses to show more respect to patients.”

- “I have just accepted it [illness] as part of life. I've never had emotions or anything like that. I am nearly 90 years old.”

- “Can't complain about anything. I've been very pleased with the treatment I've received here.” (talking about the Hospice)

- “No communication. Lack of information.”

- “I am going to the hospice. They are not offering any care; it is more of a social thing; getting out of the house for one day per week. The first day I went there, I didn't like it; I was frightened. I don't really need it because I have my family. My care there is different than the

other patients' but I can't fault it in any way. I quite enjoy it but my need is not as great because I am physically and mentally well enough.”

- “I was practically neglected when I was in hospital. I wasn't fed for 3 days because they had me mixed up with another patient (of the same name). (A family member who was present during the conversation added: “The service was exceptionally bad. I was shocked. No communication”)

- “I can't complain about anything to do with my care. People are under too much pressure. They want to give people the time but they can't.”

- “The system in the NHS is rubbish. It's not the doctors' fault. You have to stand and argue your point. The system is utterly ridiculous. They don't treat people as people; they treat them as statistics. Most of it comes down to common sense but as far as I gather the medical staff are not allowed to use common sense.”

- “After coming to the hospice my care has become much better because I didn't know what to expect or what to ask for. Nobody tells you really. You've got to be somewhere like here to figure things out.”

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