

**SPECIFIED PLACE OF CARE STUDY**

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Sponsor: South Devon Healthcare Foundation Trust.

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### **Acknowledgements**

Our thanks to:

The patients and carers who gave their time to participate in the study.

South Devon Healthcare Foundation Trust, Rowcroft Hospice Specialist Palliative Care Team and the Primary Care Teams in Torbay, Teignbridge and the South Hams.

## **EXECUTIVE SUMMARY**

### **Background and Aims**

A number of national initiatives have highlighted the need to improve end of life care for patients with both malignant and non-malignant disease. The Gold Standards Framework, Liverpool Care Pathway for the Care of the Dying Patient, Preferred Place of Death Document and the End of Life Strategy all emphasise that care should be provided in the place of the patient's choice. Despite the evidence suggesting that the majority of people would wish to die at home, only 18% of people achieve this in the UK. In the South Devon Healthcare Community 22% of patients with cancer die at home, 19% die in the hospice, 43% die in hospital and 16% die in care homes.

### **The Research Question**

Where do terminally ill patients in South Devon want to die, where do they die, and why?

### **The Purpose of the Study**

- to determine the preferred place of care of patients and caregivers
- to assess the extent to which patients achieve their preferred place of care
- to determine what personal and situational variables were most likely to be associated with the achievement of the preferred place of care
- explore with primary carers and professionals what they felt were the factors influencing actual place of death
- to guide end of life service provision in South Devon.

### **Design**

The study took place in two phases; in Phase 1 patients were recruited to the study and quantitative data were collected on demographics, preferred place of death, actual place of death, and factors associated with the latter. In phase 2 semi-structured interviews were used to collect data from healthcare professionals and primary carers. The purpose of this dual approach was to provide a quantitative underpinning for the themes revealed by qualitative interviews with staff and carers.

### **Results**

The number of patients recruited to the study was lower than had been hoped for. A total of 46 patients from the South Devon Healthcare community were recruited, five remained alive at the close of the study. A total of 25 informal carers were recruited to the study and 20 underwent a tape-recorded semi-structured interview approximately seven weeks following the patient's death. 31 professional telephone interviews were undertaken with doctors, specialist nurses, district nurses, acute hospital nurses, and nursing home staff.

#### **Phase 1 - Quantitative Analysis**

21 male and 25 female patients agreed to participate in the study with an average age of 76 years. 56% were married or living with a partner and 28% were widowed. 56% expressed the desire to die at home and 37% in the hospice. In only two cases did the patient and their carer express a different preference. 18 (44%) patients died in their preferred place.

#### **Phase 2 – Qualitative Analysis**

Primary Carer Interviews:

A total of 20 primary carers were interviewed. The most striking finding was that all were satisfied that the patient died in the appropriate place, despite the preferred place of care only being achieved for the minority. The main influencing factors on where patients died fell into three themes; disease process, family support and service availability and co-ordination. Effective symptom control, general good health of the primary carer and extended family/friend support were all seen as having a major influence in achieving a home death. A good understanding of the disease process and a close, honest and open relationship between patient and primary carer were also cited by carers as key factors. Provision of services prompted the most feedback from primary carers. Despite many positive comments, all primary carers had experienced some

difficulties with services. However, it was only on one occasion that an inadequate service had been seen to directly influence failure to achieve the preferred place of care. Overall, it was poor quality of care rather than whether a patient achieved their specific wishes which caused distress to primary carers.

#### Professional Interviews:

A total of 31 professionals were interviewed. As with the primary carers, the majority felt that the place of death was appropriate, despite only a minority of patients having achieved the preferred place of care. Key determinants in achieving a home death were given as; living with a spouse/family member, extended family/friend support, open relationships between family members, good symptom control, good communication with the professionals and effective service provision. In the four instances where professionals felt that the patient had not died in the appropriate place, the 'lack of familiarity' of Out of Hours services was cited as the main factor in prompting an unnecessary admission.

### **Conclusions and Recommendations**

The finding that the majority of carers and professionals felt the patient had died in the appropriate place, together with a clear difficulty in decision making expressed by patients, primary carers and professionals, reinforces the need to be cautious when using the achievement or non-achievement of a preferred place of care as an outcome measure for success of end of life services.

Many of the findings from this study are in keeping with previously accepted evidence. Most patients wish to die at home but only a minority do so, even with the support of specialist services. Additional home services, such as more intensive nursing support, may improve the chances of a home death through better symptom control and reduced patient and primary carer anxiety in some instances.

The professionals interviewed in this study identified Out of Hours services as the main influencing factor contributing to 'inappropriate' admissions for end of life care. Primary carers also cited problems with these services. Measures to improve communication between professionals and availability of information for Out of Hours clinicians have already been implemented during the period in which the study has taken place. Further education to promote wider use of this communication system would be likely to reduce unnecessary admissions.

In line with national guidance, all professionals involved in end of life care should endeavour to elicit and meet a patient's wishes wherever possible. However, it is also vital that we are honest about the realities of the options available and the unpredictability of a patient's needs at the end of life. We should encourage patients, relatives and health professionals to have an open and flexible approach to the planning of end of life care, wherever possible, and avoid presenting choices as goals to be attained. Future targets for end of life care should acknowledge that in-patient care is appropriate for significant numbers of patients, even in cases where it was not in accord with a patient's original wishes. In addition, with the likelihood of increasing numbers of patients dying in nursing homes over the coming years, the current drive to improve end of life care in this setting is vital to improve standards and the public's perception of being cared for and dying in a care home.

## 1. BACKGROUND

The End of Life Strategy<sup>1</sup> is the most recent of a number of national initiatives such as the Gold Standards Framework<sup>2</sup>, the Liverpool Care Pathway<sup>3</sup> and the Preferred Place of Death Documentation<sup>4</sup> that highlight the need to improve end of life care for patients with both malignant and non-malignant disease. Central to all these initiatives is the principle that, wherever possible, care should be provided in the place of the patient's choice. Professionals are therefore encouraged routinely to elicit a patient's preference for place of death as part of advance care planning in end of life care. As a consequence, one of the outcome measures used to evaluate end of life services is the extent to which patients achieve their preferences<sup>2,5,6,7</sup>.

It is well established in the literature that the majority (>50%) of people, when asked, state that they would wish to die at home but only a minority achieve this in the UK<sup>7</sup>. In fact the number of home deaths has continued to fall; 27% in 1994, 22% in 2003 and 18% in 2008<sup>1</sup>.

There is growing evidence that decision-making regarding place of care is complex and subject to change as a patient's illness progresses<sup>8,9</sup>, with the preference for a home death becoming less pronounced as death approaches. This fluidity of decision-making has been noted in previous studies and most recently in a qualitative study of experienced primary care professionals<sup>10</sup>. In this paper professionals also described that decisions were frequently 'managed' or 'co-constructed' by the professional to enable the patient to make a 'realistic' choice. Thomas<sup>11</sup> found that peoples' preferences usually lent one way or the other and did not 'constitute a categorical certainty'; their preferences could be positive or a compromise in making the best of the circumstances at the time. These findings highlight some of the difficulties in determining a true and sustained preference of place of care for many patients.

Many studies have aimed to discover which factors are most significant in determining whether a patient dies at home. In 2006, a systematic review of 58 studies, with over 1.5 million patients, most of whom had cancer, rated the factors that were most likely to influence a home death<sup>12</sup>. The review found a complicated network of factors that affect where patients die but that the six strongest predictors of a home death were patients' low functional status, expression of patient preferences and their family's agreement, use and intensity of home care, living with primary caregivers and extended family support.

This study was performed in the South Devon Healthcare Community, which covers a population of over 270,000 people and is served by the local Foundation Trust, nine community hospitals and an integrated Specialist Palliative Care Service. The latter includes an 18 bed in-patient unit, well established community and hospital multidisciplinary teams and a limited hospice at home service. Currently local figures show that 22% of patients with cancer die at home, 19% die in the hospice, 43% die in acute or community hospitals and 16% die in care homes<sup>13</sup>. In South Devon we face a number of local challenges highlighted in a recent needs assessment; these include large rural and elderly populations, a high deprivation index and a high proportion of pensioners living alone. All these factors may influence an individual's choice and realization of a preferred place of death.

Although there is well documented evidence regarding where people state they would wish to die and some of the factors that increase the likelihood of a home death, there is relatively little evidence as to why people do or do not achieve their preferred place of care. Much of the data available have been derived from varied populations of patients and healthcare systems, making the results difficult to interpret at local level. Furthermore, we were concerned from clinical experience that the national initiatives to improve patients' choice and increase home deaths do not fully take into account the fluidity of decision-making around end of life care and that many professionals feel that we 'set people up to fail' by offering 'hollow' or 'unrealistic' choices. We undertook this study in order to determine more accurately the factors influencing why patients do or do not achieve their preferred place of care in South Devon and, therefore, inform local service development. In the study we sought patients' and carers' choices regarding their preferred place of care and, following the death of the patient, gathered data regarding actual place of care and possible factors influencing whether the preferred choice was achieved. We also sought carers' and professionals' views on which factors had influenced where a patient died and whether this had been the most appropriate place.

## 2. **AIMS AND OBJECTIVES**

### 2.1 **Aims**

- To explore carers' and health care teams' experience of the factors influencing actual place of death of the patient and the decision-making process associated with this.
- To guide end of life service provision in South Devon Health Community.
- To expand available evidence on this topic.

### 2.2 **Objectives**

- To determine the preferred place of care of patients and carers.
- To assess the extent to which patients achieve their preferred place of care.
- To determine what personal and situational variables are most likely to be associated with achieving the preferred place of care.
- To explore with carers and professionals what they feel were the factors influencing actual place of death and why these factors were, or were not, important.

### **3. DESIGN AND METHOD**

#### **3.1 Study Design**

The study was conducted in two phases. In phase 1, patients and an identified primary carer (where present) were recruited and quantitative data collected with regards to preferred place of death, actual place of death and quantitative data potentially influencing the latter. In phase 2, following the death of the patient, detailed qualitative data were collected in semi-structured telephone or face to face interviews with key professionals involved in the patients care, and semi-structured tape-recorded interviews with selected primary carers.

#### **Inclusion Criteria**

- Patients aged 18 years and over.
- Patients able to express a preference for their preferred place of death.
- Patients resident in South Devon Healthcare Community.
- Patients able to give informed consent.
- Primary carers (where present) able to give informed consent.
- Both patient and primary carer (where present) agreeable to participate in the study. However, if the patient was agreeable, but the carer declined (or there was no carer), consent was sought for participation in all parts of the study apart from carer interview.

#### **Exclusion Criteria**

- Patients judged by the assessing clinician to be too unwell to participate.
- Carers, where the patient had declined to participate.

#### **Definition of primary carer**

For this study a primary carer was defined as a family member or friend that the patient identified as their greatest support.

#### **Recruitment**

Where clinically indicated, all patients (and their primary carer where present) known to the Specialist Palliative Care Service and/or on the Gold Standard Framework register in eight selected Primary Care Teams were given the opportunity to discuss their preferred place of death with a clinician involved in their care as part of their routine management. The primary carer's independent view of the preferred place of death was also sought. Where the attending clinician felt appropriate, patients fulfilling the criteria above were then offered recruitment to the study. Consent was taken from the patient and primary carer, where present, either by the attending clinician or the research nurse a minimum of 2 days later.

Key professionals of all recruited patients were contacted during the first two weeks following the death of the patient to arrange a semi-structured telephone or face to face interview, until saturation was reached.

Primary carers were contacted by post between 6-8 weeks after the death of the patient, notifying them that they would be contacted by telephone at a particular time. This letter offered the opportunity to opt out of the study and not be contacted by the return of a pre-addressed card or return phone call. If neither a card nor telephone call were received, the research nurse telephoned to arrange a tape-recorded interview date. The researcher contacted the Specialist Palliative Care Team prior to the interview process to elicit any significant concerns that may unduly distress the carer or influence their bereavement.

#### **Approvals**

Ethical approval was granted by the Devon and Torbay Research Ethics Committee.

Trust sponsorship was provided by South Devon Foundation Healthcare Trust.

Progress of the project was monitored by the Sponsor and the Peninsula Primary Care Research Management & Governance Unit.

## **3.2 Study Method**

### **3.2.1 Phase 1 - Quantitative data collection (see Appendix c)**

On recruitment to the study and following the consent of the patient (and primary carer where appropriate), data were collected from the Specialist Palliative Care or Primary Healthcare Team's records or directly from the patient/carer at time of consent with respect to:

- Preferred Place of Death (patient and primary carer).
- Demographics (age, gender, marital status, geographical area).
- Diagnosis (cancer/non cancer).
- Living arrangements (living alone, living with carer, living with non-carer, living in care home, living in sheltered accommodation).
- Self-reported health status of carer (very good, good, fair, poor).

After death of the patient, data were collected from professionals and relevant notes relating to:

- Actual place of death.
- Use of services (depending on place of death) and pathways.

In addition, the data collection sheet included a free text section where comments were recorded from professionals, patients or carers regarding issues such as decision making or the feasibility of achieving a preferred place of care.

### **3.2.2 Phase 2 - Qualitative Data Collection**

#### **3.2.2.1 Professional Interviews**

During the telephone or face to face interviews, the professionals were asked a series of open questions with the aim of eliciting whether the patient died in their preferred place, what they felt were the factors influencing this outcome and whether they felt this was the appropriate place of death for that individual (Topic Guide Appendix d).

#### **3.2.2.2 Primary Carer Interviews**

The topics covered during the primary carer interviews were similar to that of the professionals and as numbers increased other topics were included to test themes developed from earlier respondents. Respondents were encouraged to talk freely about the period prior to the death; this included whether they felt the patient died in the most appropriate place, in their preferred place and any issues related to care provision. The researcher explored what respondents felt the key factors were in patients achieving or otherwise their preferred place of death, and also any specific thoughts they had about the development of services to support patients and carers more effectively in the future. The interviewer discontinued the interview for short periods on occasions where the carer became too distressed to continue. All respondents were debriefed and asked if they had any worries or concerns resulting from the interview. All carers were advised of contacts for bereavement support if desired.

## **3.3 Data Management and Analysis**

Information from the data collection sheets was entered into an Excel spreadsheet. Patients were identified only by their survey number. The spreadsheet was kept on a password-protected network. The data were imported into an SPSS (v17) file for analysis. Because of the relatively low numbers in the study, analysis was restricted to descriptive statistics with frequencies and means (or medians) tabulated.

The semi-structured professional telephone or face to face interviews were recorded by the researcher and entered into Nvivo 7, a qualitative software programme (QSR International Pty Ltd). The primary carer semi-structured interviews were tape-recorded, transcribed and also entered into Nvivo 7. Nvivo 7 is a software programme used when a deeper level of analysis is required on large volumes of rich text information. The programme removes many of the manual tasks associated with classifying, sorting and arranging information, giving more time to explore trends, build and test theories. The codes were refined inductively into themes and sub themes by two coders and, following verification with the additional third coder, they were tested in subsequent interviews. The development of themes was overseen by regular meetings of the

steering committee. Using a phenomenological approach in the analysis of the interviews allowed for the collection of data relating to people's experience that cannot be covered by quantitative measures alone.

## **4. RESULTS**

### **4.1 Response Rates**

In total 54 patients were approached for inclusion in the study. Forty-six patients agreed to participate; eight declined or became too unwell to participate prior to consenting. Of the 46 patients, 30 had primary carers who also consented to the study. Two patients requested that their primary carer was not approached for inclusion due, in one instance, to psychological problems and, in the other, to general frailty. The remaining 14 patients either did not name a primary carer or the clinical situation precluded recruitment to the study. No carer declined to be involved in the study when approached.

A total of 26 patients were recruited and consented by the hospice in patient unit, 19 by the community palliative care team and one by the acute hospital palliative care team. There were no referrals from the eight primary care teams selected for inclusion in the study.

A total of 24 primary carers were approached for inclusion in phase 2 of the study and, of those, four declined. Two gave their reasons by telephone as being too distressed with their bereavement, and two returned cards declining without reason. Of the 20 interviews tape recorded, 18 were recorded in the primary carer's own home and two in the hospice setting. Two of the interviews failed to record; in both instances notes had been written soon after the interview and were included in the study.

A total of 31 professionals were approached for interview and none declined. The professionals were employed in the hospice, acute hospital or primary care settings. Twenty one participated in telephone interviews and ten face-to-face interviews.

Due to both carer and professional interviews being conducted until saturation, interviews were undertaken with the both primary carer and the key professional for 16 patients.

At the close of the study five patients remained alive.

#### 4.2 Phase 1 - Quantitative Data and Discussion (see Appendix e)

*The Participants.* Forty-six patients were consented for the study and 41 had died by its end. All patients were known to the Specialist Palliative Care Service. Our quantitative analysis was limited by the low numbers and we present here mainly descriptive information.

The mean age of the patients was 76 years. Other demographic information is given in Table 1, below. The mean time between consenting and death of the patient was 29 days.

**Table 1 – Demographics and Diagnosis**

|                                   | Number (%) Patients |
|-----------------------------------|---------------------|
| Mean age                          | 75.7                |
| Male                              | 21 (45.7)           |
| Female                            | 25 (54.3)           |
| Cancer                            | 39 (84.8)           |
| Non-cancer                        | 7 (15.2)            |
| Single/Divorced/Separated/Widowed | 20 (43.5)           |
| Married/Co-habiting               | 26 (56.5)           |

*Preferred place of care.* Table 2, below, shows the stated preferences for patients' place of care. The spread of preferences was in keeping with previous studies. Where we had responses from both the patient and carer, they were largely in agreement, except in two cases, where the patient wished to die at home but the primary carer's preference was for hospice care.

**Table 2 – Preferred Place of Death**

|          | Number (%) Patients |
|----------|---------------------|
| Home     | 26(56.5)            |
| Hospital | 3(6.5)              |
| Hospice  | 17(36.9)            |

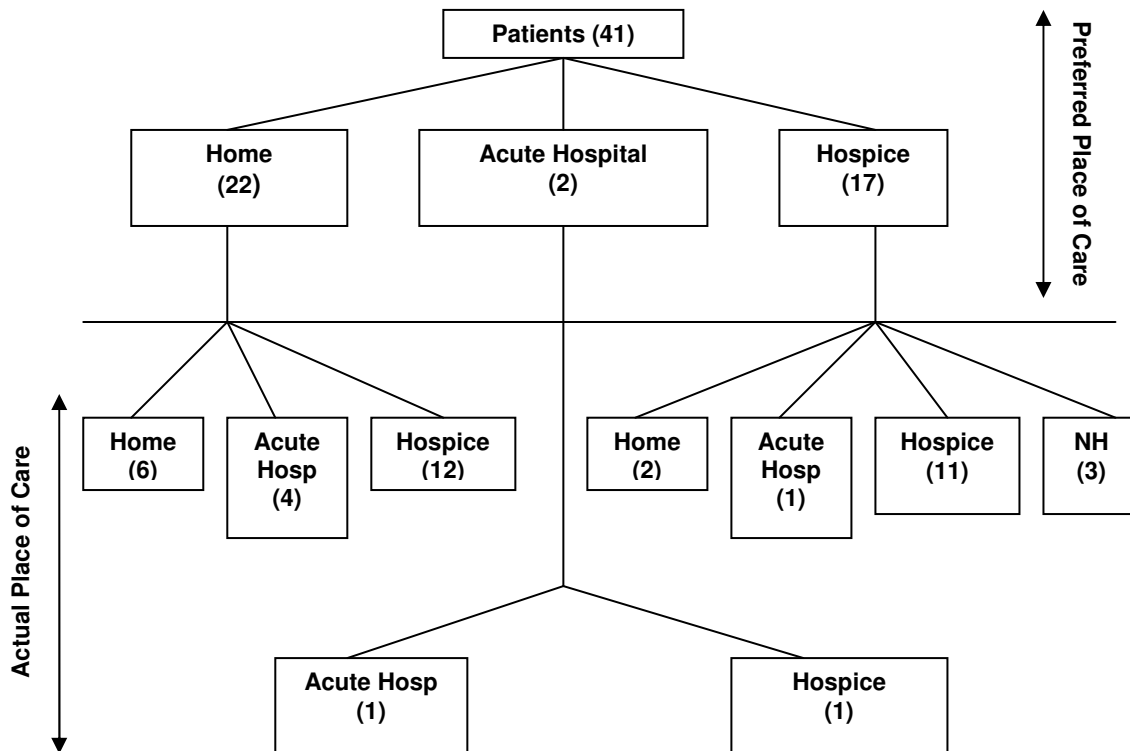
*Achieving preferred place of care.* Overall, 18 of the 41 patients in the analysis achieved their preferred place of care (44%). The actual place of death and whether this was consistent with their stated preference are shown in Table 3, below.

**Table 3 – Actual Place of Death**

|                                       | Place of Death |         |                |              | Total |
|---------------------------------------|----------------|---------|----------------|--------------|-------|
|                                       | Home           | Hospice | Acute Hospital | Nursing Home |       |
| Preferred place of death achieved     | 6              | 11      | 1              | 0            | 18    |
| Preferred place of death not achieved | 2              | 13      | 5              | 3            | 23    |

Patients' preferred and actual place of death are illustrated in Flow Diagram 1, below.

**Flow Diagram 1: Preferred and Actual Place of Death**



NH : Nursing Home

Twenty two patients wanted to be cared for at home, 17 in the hospice and two in the acute hospital. It can be seen that, of the 22 patients who wanted a home death, only six (27%) achieved this. Of those that did not, 12 died in the hospice and four in the acute hospital. Restricting the analysis to those patients whose home was stated as 'suitable' makes no difference to this proportion (i.e. all 22 homes were considered suitable for end of life care). Patients wishing to die in the hospice were more likely to die where they wished; 11 of the 17 (65%) who wished to die in the hospice did so.

*Gender and Diagnosis.* The gender and diagnosis of the patients are shown in Table 4, below. There was no association between gender and a stated preferred place of care or whether this was achieved. However, it was noteworthy that four out of five patients with non-cancer diagnoses did not achieve their preferred place of care in comparison to 19 out of 36 with cancer. These numbers were too small for a formal test of significance.

**Table 4 – Gender and Diagnosis for Achievers and Non-achievers of Preferred Place of Death**

|            | <b>Preferred Place of Death achieved (18)</b> | <b>Preferred Place of Death not achieved (23)</b> |
|------------|---|---|
| Male       | 9   | 11  |
| Female     | 9   | 12  |
| Cancer     | 17  | 19  |
| Non-cancer | 1   | 4   |

*Living Alone.* For the 14 patients who lived alone and/or had no carer, eight wished to die in the hospice and six at home. The actual place of death for this same group was six in the hospice, two in nursing homes, three in hospital and only one at home. Two patients remained alive at the end of the study. For the 32 patients who had carers and did not live alone, 20 wished to die at home, nine in the hospice and three in hospital. The actual place of death for this group was 16 in the hospice, seven at home, five in the hospital and one in a nursing home. Although the numbers of patients were too small to infer statistical significance, it is noteworthy that the figures suggest patients who had no carer and/or lived alone were more likely to state a preference for in patient care and more likely to be admitted than those patients who lived with carers.

#### 4.3 Data Sheet - (see Data Sheet comments - Appendix f)

The data sheet contained sections for open ended comments from professionals, patients and primary carers. The additional comments were recorded during the consenting process by the consenting professional or research nurse. The data collected related to whether end of life care could be provided in the patient's own home, patients and carers preferred place of care, living arrangements and services used. Two main themes emerged from the collated comments.

##### 4.3.1 Intensity of Home Care

A large number of comments from the professionals related to whether end of life care could be provided in the patient's home. The comments generally raised concerns regarding the level of support a patient and carer may need to manage at home or reference to living arrangements that would preclude home care. There was a clear association between comments made by professionals expressing doubts as to the realistic chance of a home death and this not being achieved. It was striking that on the occasions when a patient failed to achieve their preferred place of care, patients, primary carers and professionals alike had expressed doubt about the level of support needed to enable management of death at home. This finding suggests insight not only by the professionals involved into the challenges of providing care at home, but also by patients and relatives.

On eight of the 11 occasions that the patient had achieved their wish to die in the hospice, the professionals had commented that it would not have been possible to deliver appropriate care at home, either because the patient lived alone or very large packages of care would have been needed.

##### 4.3.2 Decision Making Process

Many of the professionals, who were involved in the initial recruitment of subjects to the study, highlighted the difficulties that patients and their primary carers had encountered when asked to make a 'tick box' decision regarding their preferred place of care. Frequently patients and carers reported feeling that the future was too uncertain to be confident in their decision making. This was expressed by one primary carer who stated:-

- *' I don't quite know how to answer the question as I had never cared for a dying husband before',*  
(Consenting 045: Female)

The complexities of decision making were often referenced on the data sheets with patients, primary carers and professionals 'qualifying' choices with statements such as 'if there is enough care available' or 'if the primary carer can continue to cope'.

This difficulty in decision making regarding place of care has been shown in many previous studies<sup>14,15</sup>. Patients' and carers' preference for place of care may change over time with more choosing in patient care with advancing illness<sup>9</sup>. In a qualitative study of factors influencing decisions around end of life care of eight cancer patients within a rural community, McCall and Rice<sup>8</sup> found the main influences were related to carer resource and support, patient past experiences, and communication issues not only with family but also with healthcare professionals. Preferences were not simple choices but a complex synthesis of the uncertainties of the disease process and other factors in their lives. More recently Munday et al<sup>10</sup> reported that preferences for place of death frequently changed over time and were often ill defined or poorly formed in patients' minds. Our findings support growing evidence that eliciting genuine and sustained choices for end of life care is frequently challenging and confounded by many factors.

#### 4.4 Phase 2 - Qualitative Data and Discussion

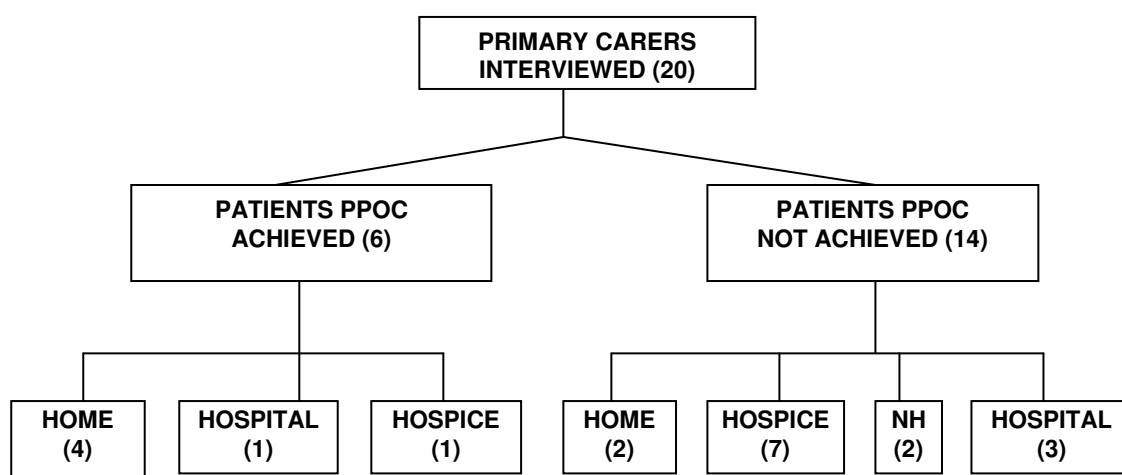
Twenty primary carers were interviewed, 13 female and seven male. All were closely related to the patient and the majority were of an older age group.

| Relationship to Patient | Number (%) |
|-------------------------|------------|
| Spouse                  | 13 (65%)   |
| Daughter                | 3 (15%)    |
| Son                     | 2 (10%)    |
| Nephew                  | 1 (5%)     |
| Niece                   | 1 (5%)     |

Eighteen (90%) primary carers were in agreement with the patient regarding their preferred place of care. All appeared highly committed to achieving the best possible care and fulfilling the wishes of the patients.

Of the 20 patients whose primary carers were interviewed, 13 had recorded a preferred place of care as home, six the hospice and one the acute hospital. The actual place of death and whether this was the patients preferred place are illustrated in Diagram 1.

**Diagram 1: Actual place of death for patients whose primary carers were interviewed**



NH : Nursing Home

#### 4.4.1 Primary Carer Interviews

##### 4.4.1.1 Preferred versus appropriate place of care

One of the most striking outcomes from the carer interviews was that all were satisfied that the patient had died in the appropriate place despite the preferred place of care only being achieved in the minority. However, there was some evidence that this had been an unwelcome 'compromise under the circumstances' rather than 'an ideal'. This occurred on two occasions when patients were transferred from the hospice to a nursing home after their condition stabilized.

- *"mum doesn't want to move out... we know this is not a long term placement... it would be nice to stay there (the hospice) till the end but having said that when she did die she was in her own room...she had privacy whereas in an open ward situation she didn't have that"* (Interview: 009 Male).
- *"(the hospice staff said) although we love to have you, we do need the bed space ... so.. they said will you agree"* (Interview: 006 Female).

The issue of patients dying in the appropriate place rather than in their place of choice has been explored by a number of authors<sup>16,17,18</sup>. In a Canadian study, Brazil et al<sup>16</sup> found that 92% of caregivers reported in semi-structured telephone interviews that the place of death of their relative had been appropriate despite not being the stated preference for 30%. However the percentage of home deaths was considerably higher than in our study at 56%. In a postal questionnaire of 214 bereaved relatives whose patients had been cared for by Hospice at Home services, the quality of patient and carer support rather than where the patient had died was shown to be of primary importance<sup>18</sup>. The findings in this study support an acceptance on the part of primary carers that an alternative place of care was in the patient's best interests despite this being contrary to their original wishes.

#### 4.4.1.2 Factors influencing achievement of preferred place of care

Three major themes emerged from the analysis of primary carer interviews as the most significant factors influencing whether patients achieved their preferred place of care:

- Disease Process
- Family Support
- Service Co-ordination and Availability

##### 4.4.1.2.1 Disease Process

###### Symptom control

Symptom control was regarded as a key influencing factor affecting where patients died by all of the primary carers. Each of the patients who died at home was described as having either minimal symptoms or very good pain and symptom control. There was also evidence suggesting that the primary carers acknowledged that if this had not been the case they probably would not have been able to manage at home.

- *"the fact that his dying was reasonably comfortable his pain...discomfort was well controlled".*  
(Interview: 045 Female)
- *"at the end of the day he wasn't in pain and he was quite calm so it was lovely really"*  
(Interview: 028 Female)
- *"so any medication that Dad needed was organised"*  
(Interview: 002 Female)
- *"she was able to give injections and that was the day that he was quite upset and she gave him whatever the injection was more or less straight away"*  
(Interview: 010 Female)

The burden of increasing symptoms was regarded as the most likely cause of a reversal of a preference for dying at home. In some instances, this burden was related to the actual physical management of symptoms, such as pain, or incontinence, and, in others, to the psychological distress caused by the symptoms to both patient and primary carer.

- *"...the medication was beyond our limit so we...he had...it had to be given by qualified staff which were all here to give it to him"*  
(Interview: 006 Female)
- *"she started to lose very heavily and it became a point so... its unbelievable, one night I changed her bed here three times, her nightdress four times I washed this floor from here to the bathroom, the commode...I literally didn't sleep I was with her constantly and then it came a point where my daughter said you can't keep her here dad "*  
(Interview: 037 Male)
- *"I suppose ... in my heart ... I knew that although I'd made a promise he was better there because of this agitation "*  
(Interview: 049 Female)

- *“she was very apprehensive before I took her in but on...on the flip side she was in a lot of pain when I took her in so we took her in, we settled that and within a day I could just see the difference in her was unbelievable”*  
(Interview: 009 Male)

The main symptoms leading to admission for those nine patients who would have liked to die at home were pain, breathing difficulties, incontinence, agitation, distress and vomiting; each patient experienced more than one symptom.

### **Fear and anxiety**

Feelings of fear and lack of ‘safety’ were expressed by 16 of the primary carers, and either related to themselves or the patients or both. The overwhelming nature of these feelings had directly led to six patients being unable to achieve a home death. The fear in many instances was as a result of the actual pain experienced by patients and in others it related to both the patient’s and the primary carer’s expectation that the pain would worsen as the disease progressed. For other patients and relatives it was a more generalised fear of approaching death.

- *“I was so worried that he would be in such terrific pain at the end and how on earth was I going to cope with it”*  
(Interview: 006 Female)
- *“she said I’m frightened.. and it cut me in half.. I cuddled her and loved her”*  
(Interview: 037 Male)
- *“it’s really scary when you’re in that situation like we were with my dad”*  
(Interview: 033 Female)
- *“I was so frightened... this is the thing ... I was so frightened of me being with him on my own ...anybody being with him for that matter and him dying fighting for breath ... that was what was frightening me more than anything and I thought that could happen when I’m here on my own with him and I won’t know what to”*  
(Interview: 024 Female)

In the majority of instances where the patient had been admitted for in patient care at the end of life, the primary carers described themselves as becoming increasingly insecure about their capabilities of managing the patient’s worsening condition. Under these circumstances, it was clear that comfort became more important than achieving an original preferred place of care. For many carers, it had been a relief to hand over the responsibility of decision making and care to professionals.

- *“he couldn’t keep anything down he wasn’t eating or drinking or anything but prior to that I’ve got to say that day when I said I couldn’t cope any longer”*  
(Interview: 006 Female)
- *“on that last morning he said to my mum I want to go into the hospice because he had such a terrible night and he was vomiting this liquid that looked like blood or something...it was dark red... my mum was so relieved because she couldn’t manage him getting out of bed she couldn’t manage getting him onto the commode”*  
*“From then on it was fine because you feel safe, you knew you had an expert who was caring for you”*  
(Interview: 033 Female)
- *“I knew he was safe and that was the thing... I knew he was safe”*  
(Interview: 024 Female)

The influence of poor symptom control and patient/carer anxiety found in this study has been well established in the literature. A prospective study looking at the preferred versus actual place of death of patients known to palliative care services, uncontrolled symptoms and pressures on carers were the most frequent cause of a change of preference at the end of life, with many opting for a hospice or hospital admission<sup>19</sup>. On further analysis, the professionals involved felt that only a minority of those admitted could have been cared for at home had additional resources been available in the community. Other studies have produced similar findings, with symptom control

and unmanageable demands on carers being the two primary reasons for admission at the end of life<sup>9</sup>.

### **Unexpected events**

There was recognition by carers that, in some instances, unexpected changes in a patient's condition were responsible for determining the place of death. For instance, where a short stay in the hospice or hospital for symptom management had been envisaged by the primary carers, either a continuing or sudden deterioration in the patients condition had led to a hospice or hospital death without a conscious decision having been made to change the initial preference.

- *"that was the plan - respite you see... so all the time he was going to come home but things didn't work out"*  
(Interview: 049 Female)

Where such events had taken place, the primary carers appeared to be accepting of the changes, viewing them as a 'force of circumstances' rather than a process which either they or healthcare professionals could influence.

### **Understanding of disease process**

The carers reported that all six of the patients who achieved their preferred place of care had a good understanding of the diagnosis, had felt fully involved in the diagnostic process and had been very clear about the terminal nature of the illness.

- *"we knew things were coming to an end, nothing was kept from him"*  
(Interview: 002 Female)

Conversely, in five of the 14 instances where a patient did not achieve their preferred place of care there was either confusion about the diagnosis or problems in accepting the reality of progressive disease, either on the part of the patient or carer or both.

- *"we had no idea this was coming up on us...we had no idea it was creeping like a snake through the grass and then all of a sudden it would turn into an express train and take us on a ride to hell..."*  
(Interview: 037 Male)
- *"then for me there's still confusion over... where he had cancer"*  
(Interview: 033 Female)
- *"he would say to me I know you don't like to talk about it but I'm ... I won't get better but I would never allow him to say that ... I'd say to him you don't know that"*  
(Interview: 049 Female)

Thus, there appears to be an association between the understanding of a patient's illness and whether they achieved their desired place of care. Lack of understanding and acceptance may impair communication between the patient and primary carer and also with healthcare professionals making planning ahead to comply with a patient's wishes more difficult<sup>20</sup>. Heide's study<sup>17</sup> found professionals reported that patients dying in an institution were less frequently 'ready to die' than those dying at home. Patients' early awareness of the terminal nature of their illness has been associated with an increased likelihood of a home death and individuals found to be more 'optimistic and avoiding the true prognosis' were more frequently admitted for in-patient care<sup>9</sup>. Other authors have drawn similar correlations between a patient's understanding or acceptance of their diagnosis with their sense of control and this, in turn, allowing them to influence their end of life care<sup>21</sup>.

#### **4.4.1.2.2 Family Support**

##### **Primary carer**

As with other studies, we found that in each of the instances where death occurred at home, whether this was the stated preferred place or otherwise, the patient was living with a female spouse. The need to provide nursing and personal care combined with daily household tasks appears to have been managed by female caregivers with more confidence than their male

counterparts. There is common acceptance in the literature<sup>12,21,22,23</sup> that the availability of care from relatives on a 24 hour basis, and being cared for by a female spouse are strongly associated with the likelihood of a home death<sup>24,25</sup>. In our study, primary caregivers who were more distantly related to the patient often had other responsibilities making the commitment to the intensity of care required difficult to manage.

In this study, each carer who had managed the patient at home had described themselves as being in very good health and had identified this as an important factor. Seventeen primary carers described the burden of physical care required to manage a patient at home, with many recounting instances of struggling to manoeuvre frail and sick patients. In three instances this was a decisive factor leading to admission.

- *“but I sat her in her lounge and then I couldn’t get her out and I’m there stuck in my garden, so in the end I just...where do you get the strength from...I put my hands under her arms and I literally lifted her out and we shuffled back up and I got her up in the steps and got her indoors”*  
(Interview: 037 Male)
- *“a lot of people trying to look after people are old and frail - I am young and fit”*  
(Interview: 018 Female)

Two primary carers reported that their patients had changed their preference of place of death from home to the hospice due to their concerns about the level of physical demands they were placing on their carers.

Therefore, in accord with previous studies<sup>16,25</sup>, there appeared to be some relationship between the health of the primary carer and the likelihood of a home death. However, this connection should be viewed with caution as a number of other primary carers in the study whose patients had not achieved a planned home death, also described themselves as fit and well.

In the six cases when a home death was achieved, the primary carers cited the closeness of their relationship with the patient as a key factor in achieving this. The strong need to be together and their total commitment to caring for each other was described as being essential in sustaining them through challenging times.

- *“What helped me most ?...well I suppose it was just love and what he wanted .....I don’t know...that’s all I can say really is the commitment and you know ...he deserved it”*  
(Interview: 030 Female)
- *“to be able to go to bed together to be to be near each other and I used to wash him every day and you put him in his clean pajamas and we just spent all day together”*  
(Interview: 010 Female)
- *“togetherness, just our cooperation and understanding of each other completely... our closeness... love I suppose you call it ... I love him now”*  
(Interview: 039 Female)

Whilst in nearly all the other cases, where death occurred outside of the home setting, primary carers appeared to have a close relationship with the patients, they did not explicitly state the need to be together as an influencing factor.

### **Extended family support**

The achievement of end of life care at home has been shown to depend not only on the primary carer but also on the availability of family and friends<sup>12,22,24</sup>. This finding was reinforced by the primary carers who acknowledged that without this extra support they were unlikely to have coped in the six instances when death occurred at home.

- *“I was lucky you know... my daughter had been with me most of the week”*  
  
*“I mean I had all the family ... my son...daughter...sister “*  
(Interview: 030 Female)

- *“She has been with us all the way through the five years and...we relied on her a tremendous amount...I think having a family close makes such a difference such a difference”*

*(daughter’s) husband used to come and sit while we went out together as a family”*  
(Interview: 002 Female)

In 13 of the remaining cases, there were a variety of reasons that limited the intensity of home support available from primary carers and extended family, including other carer commitments and living at a distance.

### **Burden of guilt**

Just under half of the primary carers described feelings of guilt. In the majority of instances this was related to their perception that they had failed to provide the best standards of either physical or emotional care for their patient. One carer described feeling that his wife had been neglected during an admission to hospital and resulting guilt that he had not spent more time with her during this period.

- *“nobody had loved her...looked after her ...even talked about her...I done the worst thing I’d ever done in my life...the thing I cannot live with .....the thing I shall take to my grave....I left her there (in hospital)... I stayed with her an hour and because I loved her to have her rest time (I went) because she wouldn’t settle whilst I was there”.*  
(Interview: 037 Male)

Two primary carers had experienced a great sense of failure in being unable to fulfil their patient’s wishes to be cared for at home. On both these occasions, symptom control had been the reason for admission. Even the clear recognition of the need for in patient care to improve symptom control had not allayed the primary carers’ profound feelings of guilt.

- *“we wanted him to stay at home.....then he had dreadful pain one night ..... and I hung on because he didn’t want to go into hospital but he had to go in ..... you know we kept him virtually all night in extreme pain and it haunts me a bit because..... I said what will they do if he goes into the hospice, all the unknown isn’t it”*  
(Interview: 049 Female)

In a study exploring the relationship between informal care requirements and where patients die, Visser et al<sup>24</sup> found that the perceived burden of care was greater in primary caregivers of patients who died in an institution than those who cared for someone at home. This was attributed in part to a sense of failure or guilt in handing over care to professionals. However in a quantitative study looking at informal carer bereavement outcomes, the retrospective perception that the place of death had been ‘right’ was more important than achieving the original preference<sup>18</sup>. The feelings and experiences of primary carers are clearly complex and influenced by numerous factors, only some of which will be related directly to the care the patient receives. When interpreting our results it is important to acknowledge that our carers were all within the first three months of bereavement. As it has been well established that guilt feelings may frequently be present during this phase<sup>26</sup>, it is possible that our findings may be significantly influenced by a normal grief reaction.

#### **4.4.1.2.3 Service Co-ordination and Availability**

Primary carers’ experience of services was very variable and provoked much feedback in the interviews. Given this, it was surprising that on only one occasion was a direct relationship made by a primary carer between lack of service provision and failure to achieve the preferred place of care; this involved a delayed discharge from hospital. On two other occasions, carers would have preferred patients to stay at the hospice rather than be transferred to a nursing home, although this was not specifically viewed as a failure of service provision. Overall, it was poor quality of care rather than whether a patient achieved their specific wishes which caused distress to primary carers.

There were eight negative comments about primary care, seven of which related to poor service and one to lack of access. Four carers expressed negative comments about specialist palliative care; three relating to service provision and one to inaccurate prediction of prognosis. Seven primary carers reported concerns about hospital diagnosis and treatment and six about social services, all relating to poor co-ordination. On three occasions primary carers were very distressed

by their experience of perceived poor service. The first related to poor nursing care and discharge coordination from the acute hospital.

- *“the room looked like it had never been looked at...a single room just by the nurses station and her dirty clothes were still on her with blood and everything on there... no care had been taken and the nurse had come out and they just left her there.. almost in a foetal position in the bed totally alien to my lovely (wife)”*  
(Interview: 037 Male)

The second occasion related to poor coordination of patient care by social services:

- *“yes but that did not work at all, it was so badly organised it was unbelievable”*  
(Interview: 022 Male)

The third instance involved the lack of compassion shown by a visiting GP from the local on call service:

- *“on the doorstep he just turned round to me he said ahh..you do realise that ..your husbands going to die and I said well yes I do know that.. he said well it’s going to be very soon.. it could be tonight and he just walked off and left me... I had nobody”*  
(Interview: 030 Female)

There were four other instances of problems encountered with Out of Hours services, though these were connected with coordination and availability, rather behaviour of staff.

- *“and we rang for the nurses because we thought, you know, they would know what to do but the unfortunate situation was that we couldn’t contact the nurses because we were between the day the girls going off (and the night staff coming on duty)”*  
(Interview: 010 Female)
- *“I had a phone call saying that (the nurse) was needed more urgently somewhere else that night...my son said what could be more urgent than .... I mean he was two days away from dying and she was needed more urgently somewhere else so obviously they haven’t got enough staff really”*  
(Interview: 030 Female)

However, there were very many positive comments about the experiences of various services and widespread acknowledgement of the important role some had played in caring for patients both at home and in in-patient facilities. For many carers the difficulties encountered with care provision were viewed, in the main, as either frustrations or obstacles to be surmounted.

- *“yes ...very happy with GP services”*  
(Interview: 036 Male)
- *“but you know the nurses were great.. so attentive you know...sit and talk to him talking through everything”*  
(Interview: 030 Female)
- *“having so many people in you got to know them and they almost became part of the family”*  
(Interview: 002 Female)

The impact of service provision on achieving a preferred place of care has been investigated by a number of authors over recent years<sup>5,12,19,21,22,25,27</sup>; a change of preference at the end of life may be associated with not only availability of services but also to poor quality of care and lack of co-ordination. There is also evidence that it may be difficult to sustain end of life care at home for a prolonged period<sup>28</sup>. It is possible that poor service experienced by some of our primary carers led to an insidious lowering of their ability to care for the patient at home, leading to an eventual admission that they themselves did not associate with inadequate service provision. The reassurance given to the primary carers by frequent and regular access to the professionals was evident in their comments about the services. Studies have identified<sup>16,25,29,30,31,32</sup> that consistent involvement of the general practitioner, district nurse and palliative care services have improved the quality of end of life care and also lowered the likelihood of admission to hospital, although none of these studies were based in the United Kingdom.

#### 4.4.2 Professional Interviews

All 31 of the professionals interviewed were either doctors or nurses from Primary Care teams, Specialist Palliative Care Services or nursing homes.

**Table 5 – Professional Interviewees**

| Profession                                 | Number |
|--|--------|
| Hospice Doctors                            | 3      |
| Palliative Care Consultants                | 2      |
| General Practitioners                      | 2      |
| Community Nurses                           | 8      |
| Palliative Care Clinical Nurse Specialists | 7      |
| Hospital Nurse Specialists                 | 3      |
| Hospice Registered Nurses                  | 3      |
| Nursing Home Registered Nurses             | 3      |

Twelve of the professionals' patients died in their preferred place whilst the remaining 19 died elsewhere.

Similarly to carers, the majority (27/31) of the health professionals interviewed felt that the place of death was appropriate despite only a minority of patients achieving their preferred place of care.

In line with previous studies and the views of our primary carers, the professionals felt that the key determinants in achieving a home death were: living with a well spouse/family member, extended family friend support, an open relationship between family members, effective symptom control, effective communication (between professionals and between professionals and patients) and quality service provision.

- *'the patient and his wife had much support from friends and family, ..... this was a key determinant in achieving a home death'*  
(Telephone interview: 030 District Nurse)
- *'I think the key reasons for having achieved the preferred place of death were:-  
Symptom's well controlled at home, family support was excellent, very good professional support more specifically, district nurses, night nurses, social services and specialist palliative care services'*  
(Telephone interview: 002 Palliative Care Nurse Specialist)

Although it can be seen that the views of the primary carers and the professionals regarding which were the key influencing factors were very similar, it is of interest to note that, the association between service provision and the achievement of preferred place of care was given significantly more emphasis by the professionals. The reasons for this difference may be due to a greater awareness of availability of care and 'best practice' of professionals compared to the primary carers.

Three professionals felt the place of death of their patient was inappropriate and one was unsure giving the following reasons:-

- *'an Out of Hours medical practitioner had been called to see the patient who was experiencing problems with uncontrolled symptoms, the nursing home was seeking advice on pain control but the medical practitioner decided to admit to the acute hospital'*  
(Telephone interview: 011 Nurse)
- *'the patient had been admitted to the acute trust with uncontrolled symptoms over the festive season and it had not been possible to organise carers before his condition deteriorated and he died'*  
(Face to face interview: 020 Palliative Care Consultant)

- *'the patient's wife was elderly, frail and panicked when her husband's condition deteriorated, she called the Out of Hours service saying she could not cope so admission was arranged. The district nurse felt if either she or the GP had been available the admission could have been avoided as they both had a close relationship with the primary carer'.*  
(Telephone interview: 034 Nurse)

A fourth professional was not sure whether the patient died in the appropriate setting for reasons similar to those given above. This doctor felt that she had a very good relationship with the couple and, if she had been available at the time of the crisis, an admission may have been averted.

- *'whether she herself had been on duty over the Christmas period – home may have been manageable'*  
(Telephone interview: 049 GP)

As illustrated, one of the key factors identified by professionals leading to a patient dying in an inappropriate place was associated with the Out of Hours service, and specifically related to a lack of familiarity of patient and family circumstances increasing the likelihood of admission. With changes in Out of Hours care in England over the last decade, these services are generally provided by large scale GP cooperatives. As patients are seen by clinicians who are unlikely to have direct knowledge of their case, continuity of care may be compromised. There is a consensus in the literature that continuity of care is a key element in the quality of care for a dying patient<sup>2,11,30,33,34</sup>. Furthermore, a number of studies have drawn a relationship between the frequency of 'own General Practitioner' home visiting and the chances of dying at home<sup>16,25,30,35</sup>. Lack of information regarding a patient's circumstances for Out of Hours clinicians may lead to more problems with symptom control and potentially unnecessary admissions<sup>36</sup>.

These challenges in providing appropriate 'Out of Hours' palliative care through on call services are well recognised and much recent work has been invested nationally and locally into improving communication between a patients 'usual team' and Out of Hours services through the Gold Standards Framework, Liverpool Care Pathway and 'Special Messaging' services. Standardised, dedicated forms for transfer of information to Out of Hours services have been shown to increase the number of 'messages' sent and these are now widespread locally and nationally<sup>35</sup>. A number of studies have found that the content of the information may be variable, with clinical details being more likely to be communicated than patients' wishes or social circumstances<sup>38,39</sup>. In a recent retrospective study of messages received by a GP cooperative in the Netherlands<sup>38</sup>, there was some evidence that when information had been transferred for palliative care patients they were less likely to be admitted. However a causal relationship could not be drawn due to the design of the study. Interestingly this study also revealed that patients in care homes were less likely to have information transferred by primary care teams than those patients at home. Overall, it is clear that improvements have been made in communication between a patient's 'usual team' and Out of Hours services. However, significant challenges still remain to minimise 'inappropriate care' due to lack of information and continuity.

## 5. LIMITATIONS OF THE STUDY

There were a number of significant limitations to this study. The number of patients recruited was lower than expected. Therefore, although there was adequate data for qualitative analysis, it was insufficient to infer quantitative significance for many of the variables. There are well recognised challenges to recruiting and retaining patients in Palliative Care studies which influenced our recruitment rate. In addition, many professionals involved commented that at the time of discussions regarding place of care, patients were frequently too unwell to be approached to participate in the study. In other instances, patients were only able to make a definite choice about what they did not want e.g. did not wish to die at home or did not want to be in hospital, and were therefore excluded. Furthermore, where professionals had felt that the patient did not have a realistic 'choice' and they had 'steered' the patient to a particular decision, they had not been able to offer recruitment.

All patients in the study were known to the Specialist Palliative Care Service and previous contact with hospice services is likely to have influenced some patients' desire to die in the hospice as well as their willingness to be admitted from home. The patients may also have had greater symptom control needs, more intensive home support and easier access to admission to the hospice than the population as a whole. We attempted, but failed, to recruit patients from eight Primary Care Teams to reduce this bias. The reason for this appeared to be that the patients for whom advance care planning was thought to be appropriate at Gold Standards Framework meetings were already known to the Specialist Palliative Care Service. Moreover, some GPs expressed the view that Specialist Palliative Care professionals were better placed to facilitate these discussions and therefore enrol subjects. Failure to recruit from Primary care teams directly may also have led to patients dying in community hospitals being underrepresented in the results.

Due to the referral pattern to Specialist Palliative Care Services, the majority of the patients had a cancer diagnosis and probably, therefore, a more predictable disease trajectory than many other patients with life threatening illnesses. This predictability may have allowed professionals to plan more effectively to meet patients' wishes regarding place of care than the general population. We observed that for the five patients with non cancer diagnosis, only one achieved their preferred place of death, whereas the proportion for cancer patients was much greater.

## 6. CONCLUSIONS

One of the most significant and surprising findings of our study was that almost all carers and professionals felt that the patients had died in the appropriate place despite the preferred place only being achieved for the minority. There was evidence that this was a compromise in some cases. We believe that this finding, together with the clear difficulty in decision making expressed by patients, primary carers and professionals, reinforces the need to be cautious when using the achievement of a preferred place of care as an outcome measure for success of end of life services.

Many of the findings from this study are in keeping with previously accepted evidence. Most patients wish to die at home but only a minority do so even with the support of specialist services. Good symptom control, living with a fit female spouse and extended family support are all important in improving the chances of a home death. However all these factors should be regarded as contributory rather than sufficient and in each case the factors involved may be complex and unpredictable. It is possible, however, that in some cases, additional home services, such as individual 24 hour nursing support, would considerably improve the chances of a home death through better symptom control and reduced patient and primary carer anxiety.

The professionals interviewed in this study clearly identified Out of Hours services as the main influencing factor contributing to 'inappropriate' admissions for end of life care. Primary carers also cited problems with these services. Availability and co-ordination of services, together with a lack of familiarity with the patient by the attending clinician were areas of greatest concern. Measures to improve communication between professionals and information available for Out of Hours clinicians have already been implemented during the period in which the study took place. However, further progress is likely to be required.

The data from primary carers suggested that those patients and families who had struggled to adjust to their diagnosis and prognosis were less likely to achieve a home death. This appeared to be related to anxiety and fear in most cases. Professionals need to be mindful that this is a cohort of patients for whom end of life care may be challenging. Early identification of these patients to allow more intensive preparation and support may improve their likelihood of being able to stay at home if desired.

Some primary carers had been left with clear feelings of guilt when their relative had not achieved their preferred place of care. This had occurred even on occasions when they recognised that in-patient care had been in the patient's best interests. In line with national guidance, all professionals involved in end of life care should endeavour to elicit and meet a patient's wishes wherever possible. However, it is also vital that we are honest about the realities of the options available and the unpredictability of a patient's needs at the end of life. We should encourage patients, relatives and professionals to have an open and flexible approach to the planning of end of life care wherever possible and avoid presenting choices as goals to be attained. Only in this way will we avoid unrealistic expectations and potentially adding to primary carers' guilt and bereavement.

Whilst meeting patients' wishes for end of life care at home wherever possible, there also needs to be a recognition that in patient care is the most appropriate option for many during the final stages of their illness. This may be particularly important to consider for those with no carer or living alone. Clearly, an improvement in communication and community services to facilitate more home deaths than currently achieved is highly desirable. However, even when intensive primary care and specialist support is available at home, symptom control needs, patient or carer anxiety, lack of extended family support, a change of mind or unforeseen circumstances may lead to an entirely appropriate admission. Future targets for home deaths should acknowledge the need for in-patient end of life care and recognise that this may be appropriate even in cases where it was not in accord with a patient's original wishes. The current projections for targets for home deaths may be neither realistic nor desirable.

## 7. RECOMMENDATIONS

### Local Strategy

In the light of professionals' and primary carers' comments, the availability and co-ordination of Out of Hours services should be reviewed. A 'Special Message' service currently operates allowing a patient's 'usual team' to provide written information about clinical condition and patients' wishes to the local Out of Hours GP service. This message is automatically prompted when a patient is commenced on the LCP but may also be sent for any palliative care patient. The message both informs the Out of Hours clinician and triggers a shorter standard response time to the call. Most patients known to Specialist Palliative Care Services and many on local GSF registers now have messages in place. However, it is less clear whether these messages are updated when a patient's circumstances or wishes change and who should take responsibility for this. For patients in care homes, it may be unclear whether sending the message is the role of the primary care team or nursing home staff. Furthermore, in some circumstances it may be optimal for clinicians in the acute sector to take responsibility for transferring this information, for instance as part of a rapid discharge for terminal care. We would recommend further education and audit to promote and monitor wider use of this system particularly for patients with non-malignant disease and those in care homes.

In-patient care at the end of life is appropriate for a significant number of patients, even though this may not be in accord with their original wishes. This may be due to symptom control needs, fear or anxiety or a change of mind with regard to preferred place of care. Local strategy needs to recognise the need for this facility, particularly in specialist palliative care beds and community hospitals to meet patients' needs appropriately. Admission for end of life care should not necessarily be regarded as a negative outcome for either the patient or their carer.

Additional home services, such as individual 24 hour nursing support, may well significantly improve the chances of a home death for some patients, through better symptom control, relieving the burden of physical care on primary carers and reduced patient and primary carer anxiety. Further co-ordination between providers of care and rapid access to continuing care funding are being developed locally to improve nursing provision at home.

### National Strategy

It was noteworthy in our study that no patient stated that they would wish to die in a nursing home, although all primary carers of those who died in a nursing home were very satisfied with the standard of care provision. Nationally, 17% of patients die in care homes and this is likely to increase over the coming years with an aging population. The current drive to improve end of life care in this setting is vital to improve standards and the public's perception of being cared for and dying in a care home.

For many patients, it is challenging to offer a genuine 'choice' as to where they would like to be cared for at the end of their life. Whilst ensuring that we continue to endeavour to meet patients' wishes wherever possible, we should also be guiding patients to realistic goals. It is therefore perhaps better to think of the outcome of these discussions as an 'appropriate decision' rather than 'a choice'. We should also encourage patients, relatives and professionals to have an open and flexible approach to end of life care and accept that any plans will need to be reviewed in response to changing circumstances.

Due to the complexities of decision making around place of care, the varied factors influencing where people die and professionals' and carers' views about where the patient died in this study, we would advise caution in using achievement of a preferred place of care as an outcome measure for End of Life services and a marker of a 'successful death'. Although potentially more challenging to determine, whether a patient died in the 'appropriate place' for their individual circumstances may be a more meaningful outcome to monitor.

## **Research**

Much of the research into end of life care, including this study, has focussed on patients with malignant disease. Due to their more predictable disease trajectory and access to services, this group of patients is not representative of the population as a whole. Further research into the factors influencing place of death and availability of services for patients with non-malignant disease and those not known to specialist palliative care would generate data more representative for the population as a whole.

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9. **APPENDICES**

- a) Application
- b) Study Timetable
- c) Data Sheet
- d) Topic Guide
- e) Quantitative Data Results
- f) Data Sheet Comments

## SPOCS

### SPECIFIED PLACE OF CARE STUDY

#### Factors influencing actual versus preferred place of death and the decision making process

#### APPLICATION

##### Background

A number of national initiatives have highlighted the need to improve end of life care for patients with both malignant and non-malignant disease. The Gold Standards Framework (GSF), Liverpool Care Pathway for the Care of the Dying Patient (LCP), and Preferred Place of Death (PPOD) initiatives all emphasise that, wherever possible, care should be provided in the place of the patient's choice. Although there is evidence that the majority of people would wish to die at home, only 22% of people with cancer achieve this in the UK<sup>1</sup>. In the South Devon Healthcare Community, 22% patients with cancer die at home, 19% die in the hospice, 43% die in hospital and 16% die in care homes<sup>2</sup>.

There is limited evidence available either locally or nationally as to why people do not achieve their preferred place of care. A number of studies have suggested that factors influencing patient decision making are complex and subject to change as their illness progresses<sup>3,4,5</sup>. Therefore, some of the discrepancy between actual and preferred place of death may be attributable to a change in decision. Other factors reported to influence actual place of death include expression of a preference for a PPOD by the patient and their family's agreement, availability and intensity of home care, living with primary caregivers and extended family support<sup>6</sup>. The data collected has been derived from varied populations of patients and healthcare systems, making the results difficult to interpret at a local level.

In South Devon we face a number of local challenges highlighted in a recent needs assessment<sup>2</sup>; these include large rural and elderly populations, a high deprivation index and a high proportion of pensioners living alone. All these factors may influence an individual's choice and realization of a preferred place of death. Currently, there are approximately 1000 referrals to the Specialist Palliative Care Service each year. Of patients known to the service, 200 die in the hospice, 200 die at home, 80 die in care homes and 320 die in hospital (acute and community hospital figures combined) each year. The GSF is a national, primary care based initiative to identify patients in the last 6-12 months of life and to co-ordinate and improve the services they receive. It is unknown how many patients are on the GSF register locally.

As a health community we are reviewing end of life care to improve both patient choice and experience of services. We are aiming to reduce unscheduled admissions to the acute sector and improve Out of Hours care, home support and equity of access to services. Data gained from this study would guide service improvement for the local community in South Devon and expand the available evidence on this topic.

A recent Canadian study combining informal carers' views and quantitative data on factors influencing actual place of death influenced the design of this study. However, the proposed project will be different in a number of characteristics including a different study population, a different healthcare system and determining PPOD prior to death, directly from the patient<sup>7</sup>.

##### Research Question

Where do terminally ill patients in South Devon want to die, where do they die, and why?

## **Aims and Objectives**

### **Aim**

Exploration of carers' and health care teams' experience of the factors influencing actual place of death of the patient and the decision making process around this.

### **Objectives**

*To determine the PPOD for patients and carers*

*To assess the extent to which patients achieve their PPOD*

*To determine what personal and situational variables are most likely to be associated with achieving PPOD*

*To explore with carers and professionals what they feel were the factors influencing actual place of death and why these factors were (or were not) important*

### **Study Design**

The proposed study will take place in 2 phases; in Phase I patients will be recruited to the study and data will be collected with regards to PPOD, actual place of death and quantitative data influencing the latter. In Phase II, detailed qualitative data will be collected in semi-structured interviews with professionals and selected informal carers.

### **PHASE I**

All patients (and their primary carer) known to the Specialist Palliative Care Service (SPCS) and /or on the GSF register in selected Primary Care Teams should have the opportunity to discuss their PPOD with a clinician involved in their care as part of their routine management. The primary carer's independent view of PPOD will also be sought. The timing of these discussions will be based on clinical need and will not be directly influenced by this study. Those fulfilling the criteria below will be offered recruitment to the study; informed consent will be required from both the patient and primary carer, where present.

Quantitative data including demographics, diagnosis, actual place of death and availability and use of services will be collected at time of consent and following death of the patient.

### **PHASE II**

Following the death of the patient, their primary carer and key professional (e.g. General Practitioner, District Nurse or member of the Specialist Palliative Care Team) primarily involved with the patient's care during their last month of life will be invited to participate in a face-to-face (for carers) or telephone (for professionals) semi-structured interview. Where death of the patient occurs in the hospice or acute sector members of the responsible clinical teams will be interviewed. Qualitative data with regards to factors influencing whether patients achieved their PPOD will be collected during the interviews.

Initial discussions with patients and carers with regards to PPOD and recruitment to the study will be conducted by a clinician involved in their management. Consent and data collection, including semi-structured interviews, will be performed by a research nurse.

One limitation of the study design is potential bias caused by the selected population of patients; only patients known to the SPCS or on the GSF register in designated Primary Care teams will be included in the study. Patients with a non-cancer diagnosis are likely to be poorly represented. In addition, uptake of the GSF register may reflect a particular interest in palliative care in local

primary care teams and the care their patients receive may not be representative of the general population. Ideally, the sample population would represent all deaths in the local area; this was considered to be too complex a project to take on locally at the present time. However, if this study proves successful, the results could be used as a basis for a study of a non-selected population.

### **Inclusion Criteria**

Patients known to SPCS and /or on GSF register in selected Primary Care Teams

Patients aged 18 years and over

Patients able to express a preference for their PPOD

Patients resident in South Devon Healthcare Community

Patients able to give informed consent

Primary carers (where present) able to give informed consent

Both patient and carer (where present) agreeable to participate in the study. (However, if patient agreeable, but carer declines, consent would be sought for participation in all parts of study apart from carer interview).

### **Exclusion Criteria**

Patients judged by the assessing clinician to be too unwell to participate

### **Quantitative Data Collection (Phase I)**

Following the consent of the patient (and carer where appropriate), data will be collected from the Specialist Palliative Care or Primary Healthcare Team's records or directly from patient/carer at time of consent with respect to:

Preferred Place of Death (patient and carer)

Demographics (age, gender, marital status, geographical area)

Diagnosis (cancer/non-cancer)

Living Arrangements (living alone, living with carer, living with non-carer, living in care home, living in sheltered accommodation)

Self-reported health status of carer (very good, good, fair, poor)

After death of the patient, data will be collected from relevant notes with respect to:

Actual Place of Death

Use of services (Social Service and Healthcare funded Carers, Marie Curie service, Hospice at Home service, Primary Healthcare Team, Site Specific Clinical Nurse Specialists and SPCS support)

Use of pathways (LCP, GSF and a local Personal Held Record Scheme)

Was death expected?

## **Qualitative Data Collection (Phase II)**

Key professionals of all recruited patients will be contacted within 4 weeks of the death of the patient to arrange semi-structured telephone interviews. Consent will be taken from the professional prior to the interview.

Primary Carers will be contacted by post between 4 and 8 weeks after the death of the patient, notifying them that they will be contacted by telephone at a particular time. This letter will offer the opportunity to opt out of the study and not be contacted by return of a pre-addressed card or return phone call. If they are still willing to be contacted, they will be telephoned to determine whether they would wish to participate in a semi-structured interview at a later date.

Semi-structured interviews with carers and professionals will be tape recorded and transcribed. Initial issues to be explored will include those listed in the interview schedule below, but others will be included in later interviews if they are thought to reflect respondents' own concerns and relevancies.

### **Interview Schedule**

Did the patient die in their preferred place?

If the patient died in their preferred place, what were the important factors which allowed this to happen? (Family members, primary health care team, professional carers, SPCS, other?)

If the patient died in a different place, why was this? (Change of preference, change of patient circumstances, change of family circumstances, lack of availability of services, other?)

Did the carer/professional feel the patient died in the appropriate place?

It is acknowledged that the dataset collected from carers is likely to be much richer than from professionals. However it was felt to be important to contact professionals sooner following death of the patient as their recall of events would be likely to diminish over time.

### **Sample Sizes and Analyses**

We shall approach all patients (and their carer) meeting the inclusion criteria described above for their permission to abstract basic data from their notes for the purposes of the research over the course of one year. Based on the last two years' data, this is likely to be about 400 patients. Assuming a recruitment rate of 70% we shall have basic data on 280 patients. Data will be entered onto an Excel spreadsheet and thence to an SPSS file. These data will allow us to describe where the preferred place of death is, as well as the proportion of patients achieving PPOD (to within +/- 5%). Binary logistic regression will allow us to assess those characteristics most likely to be associated with patients achieving their PPOD.

From patients consented during the first six months of the study we shall purposively sample carers of patients who achieved PPOD and those who did not, for face to face semi-structured personal interviews. It is likely that each group will comprise 15 to 20 interviews but they will continue until saturation is achieved. Analysis of the data will be undertaken with the use of QSR N7 software for coding purposes. A constant comparative method will be employed with findings from early interviews being used to inform the process of later interviews. Given the relatively large numbers of interviews to be undertaken it is proposed to categorise the data by developing emergent themes from the data using thematic analysis (Boyatzis 2000). Initial categories will be refined into a small number of themes and sub-themes which will form a framework for discussion of the data. Themes will be examined interpretively and reflexively and checked by other members of the research team using inter-rater reliability. Results will be reported using relevant quotes to illustrate features of each theme discussed.

### **Data Security**

Both datasets will be kept securely, in the Hospice on a password protected desktop computer. The master list linking names with survey numbers will be kept in a locked filing cabinet. Any data

leaving the hospice, for example for analysis by the University of Plymouth School of Maths and Statistics will not be identifiable.

### The Research Team

Dr Walker, Dr Sykes and Dr Scheffer are clinical leads for the community, hospital and in-patient specialist palliative care teams in South Devon, respectively. Dr Walker is the project lead.

Ms Corley leads the local LCP steering group and is the Nurse Lead for the whole SPCS. Ms Corley is currently participating in a number of local research projects.

Dr Allen has led the GSF roll-out in South Devon and is the Cancer Lead for Torbay PCT. Dr Allen is also a local, practising GP.

Mr Barton is the Coordinator of the Plymouth office of the Peninsula RDSU and will provide general methodological and management advice.

Mr Ron Hunt, user representative.

Dr Evans is a Specialist Registrar in Palliative Medicine.

In addition, the group will include

Dr Steve Shaw, UoP Department of Mathematics and Statistics as statistical advisor.

Research Nurse (tba). Responsible for data collection and day-to-day running of the study.

Secretarial support. 10 hours per week of secretarial support has been costed in. Much of this time will be spent transcribing interviews and entering other data.

The Project Steering Group will monitor general progress and identify slippages in the timetable or potential overspends. Remedial action will be decided here. In addition, the research nurse, based at Rowcroft Hospice, will be in almost daily contact with the project leader, Dr George Walker. The nurse will be professionally responsible to Sr Reine Corley, the nurse lead for SPCS.

Dr Steve Shaw from the University of Plymouth's School of Mathematics and Statistics has already provided statistical advice and will supervise the majority of the statistical analysis.

### Timetable for SPOCS (months)

|                            | 0 | 2 | 4 | 6 | 8 | 10 | 12 | 14 | 16 | 18 |
|----------------------------|---|---|---|---|---|----|----|----|----|----|
| Project Steering Group     | X |   | X |   | X |    | X  |    | X  |    |
| Training for reseach nurse | X | X |   |   |   |    |    |    |    |    |
| Testing proformas          | X | X |   |   |   |    |    |    |    |    |
| Data collection            |   |   | X | X | X | X  | X  | X  |    |    |
| Analysis                   |   |   |   |   |   | X  | X  | X  | X  |    |
| Reporting                  | X | X |   |   |   |    |    | X  | X  | X  |

Project costs are being met from a grant of £41 000 from the charity Dimbleby Cancer Care. Staff at Rowcroft are aware of the project and keen to participate, along with colleagues in primary care who have a specialist interest in palliative care. Accommodation for the research nurse, along with a networked computer and appropriate software will be provided at Rowcroft Hospice. We have indicated above that our proposed sample size for the quantitative analysis will allow us to estimate the proportion of patients who die where they want to within 5%. We feel that 70% recruitment rate is quite pessimistic and our estimate is thus likely to be rather more precise.

### Ethical Considerations

The project steering group feel that the main ethical issue which may arise during the study is potentially adding to the pressure felt by vulnerable people at a distressing time in their lives. As a Specialist palliative Care Team we are experienced in identifying and managing these issues.

Where concerns are highlighted, the patient and carer will be offered appropriate support by either the SPCS or Primary Care Team.

We will seek approval from the South Devon Local Research Ethics Committee.

### **Dissemination of Results**

The study will be submitted for publication in a peer reviewed journal.

The results will be disseminated locally and nationally via the Peninsula Cancer Network and Palliative Care Strategic Planning Group (South Devon Healthcare Palliative Care Partnership Committee). Both professionals and carers will be offered a brief summary of the results.

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**Appendix b)**

**STUDY TIMETABLE**

September 2007 – November 2007

**Study Set Up**

Ethical Approval  
Professional Education

November 2007 – October 2008

**Recruitment and Data Collection**

Quantitative data collection  
Semi – structured telephone/face to face interviews with professionals  
Semi – structured tape-recorded interviews with selected carers  
Organisation of data

October 2008 – March 2010

**Analysis and Completion of Project**

Literature review  
Analysis  
Report Writing  
Journal Submission.

SPOCS

SPECIFIED PLACE OF CARE STUDY DATA SHEET

Signed Consent Form present Yes  No

Survey Number

Date

**A. ABOUT THE PATIENT**

1. Date of Birth:

2. Gender: Male  Female

3. Marital Status:  
 Single  Divorced/separated  Married/cohabiting  Widowed

4. Area of residence:  
 Insert first part of postcode

5. Diagnosis: Cancer  Other

6. Is there a carer for the patient Yes  No  (go to 8)

7. Is the carer NOK Yes  No

**B. THE PATIENT'S CIRCUMSTANCES**

8. Living arrangements:  
 Living Alone  Living with carer   
 Living with other (not carer)  Care Home   
 Sheltered (warden controlled) Housing   
 Other  (please describe below)

.....  
 9. Could end of life care be provided in the patient's home?  
 Yes  No  (If no, please say why briefly below)  
 .....  
 .....

10. Self-reported health status of carer:  
 Very Good  Good  Fair  Poor

**C. PREFERRED PLACE OF DEATH**

11. Patient  
Patient's Home  Acute Hospital  Community Hospital  Nursing Home   
Residential Home  Hospice  Other  (*Please write in*).....  
Comments:.....  
.....  
.....

12. **Carer**  
Patient's Home  Acute Hospital  Community Hospital  Nursing Home   
Residential Home  Hospice  Other  (*Please write in*).....  
Comments:.....  
.....

**D. AFTER PATIENT'S DEATH**

13. Date of death 

|  |  |  |  |  |  |
|--|--|--|--|--|--|
|  |  |  |  |  |  |
|--|--|--|--|--|--|

14. Actual place of death  
Patient's Home  Acute Hospital  Community Hospital  Nursing Home   
Residential Home  Hospice  Other  (*Please write in*).....  
Comments:.....  
.....

15. Was death expected?  
Yes  No

16. If the patient died at home, which of the following services were being used by the patient?

|                   |                          |  |                          |
|-------------------|--------------------------|--|--------------------------|
| Social Services   | <input type="checkbox"/> | Healthcare funded carers               | <input type="checkbox"/> |
| End of Life       | <input type="checkbox"/> | SPCS Support                           | <input type="checkbox"/> |
| Primary Care Team | <input type="checkbox"/> | Other ( <i>please describe below</i> ) | <input type="checkbox"/> |

Comments: .....

.....

17. If the patient died in hospital, which of the following agencies were involved:

|                        |                          |                |                          |
|------------------------|--------------------------|----------------|--------------------------|
| SPCS                   | <input type="checkbox"/> | Specialist CNS | <input type="checkbox"/> |
| Discharge Liaison Team | <input type="checkbox"/> | Other          | <input type="checkbox"/> |

18. Use of pathways:

|     |                          |                                      |                          |
|-----|--------------------------|--------------------------------------|--------------------------|
| LCP | <input type="checkbox"/> | Personal held record "Yellow Folder" | <input type="checkbox"/> |
| GSF | <input type="checkbox"/> | Devon Docs Special Message Form      | <input type="checkbox"/> |

19. Any other comments:

.....   
.....

20. Have any of the demographic details in A or B changed (*please list below*)

.....   
.....

Completed by: PA  Other  (*write in below*)

.....

Date:

|  |  |  |  |  |  |
|--|--|--|--|--|--|
|  |  |  |  |  |  |
|--|--|--|--|--|--|

**Appendix d)**

**SPOCS**

**SPECIFIED PLACE OF CARE STUDY**

**Factors influencing actual versus preferred place of death and the decision making process**

**TOPIC GUIDE**

Did the patient die in their preferred place?

If the patient died in their preferred place, what were the important factors which allowed this to happen? (Family members, primary healthcare team, professional carers, SPCS, other?)

If the patient died in a different place, why was this? (change of preference, change of patient circumstances, change of family circumstances, lack of availability of services, other?)

Did the carer/professional feel the patient died in the appropriate place?

## Appendix e)

### QUANTITATIVE DATA SHEET RESULTS

#### A: About the Patient

There were 46 patients in the study, 21 males (45.7%) and 25 (54.3%) females.

#### Age at recruitment by gender (Q1 and 2)

|           | Male (n=21) | Female (n=25) | Overall (n=46) |
|-----------|-------------|---------------|----------------|
| Mean (SD) | 77.7 (11.0) | 74.1 (13.2)   | 75.7 (12.3)    |
| Median    | 77          | 72            | 76             |
| Range     | 54-100      | 47-100        | 47-100         |

#### Age at death by gender (Q1 and 2)

|           | Male (n=20) | Female (n=21) | Overall (n=41) |
|-----------|-------------|---------------|----------------|
| Mean (SD) | 79.0 (9.9)  | 74.1 (13.0)   | 76.5 (11.7)    |
| Median    | 78          | 72            | 76             |
| Range     | 60-100      | 47-100        | 47-100         |

#### Marital Status (Q3)

|                    | Number (%) |
|--------------------|------------|
| Single             | 3 (6.5%)   |
| Divorced/separated | 4 (8.7%)   |
| Married/cohabiting | 26 (56.5%) |
| Widowed            | 13 (28.3%) |

#### Diagnosis (Q5)

|        | Number (%) |
|--------|------------|
| Cancer | 39 (84.8%) |
| Other  | 7 (15.2%)  |

#### Is there a carer for the patient? (Q6)

|     | Number (%) |
|-----|------------|
| Yes | 38 (82.5%) |
| No  | 8 (17.4%)  |

#### Is the carer NOK? (Q7)

|                | Number (%) |
|----------------|------------|
| Yes            | 35 (76.1%) |
| No             | 2 (4.3%)   |
| Not applicable | 8 (17.4%)  |
| Don't know     | 1 (2.2%)   |

## B: The patient's circumstances

### Living arrangements (Q8)

|                                       | Number (%) |
|---------------------------------------|------------|
| Living Alone                          | 12 (26.1%) |
| Living with carer                     | 27 (58.7%) |
| Living with other (not carer)         | 2 (4.3%)   |
| Care Home                             | 1 (2.2%)   |
| Sheltered (warden controlled) Housing | 0          |
| Other                                 | 0          |
| No to all above                       | 4 (8.7%)   |

### Could end of life care be provided in the patient's home? (Q9)

|     | Number (%) |
|-----|------------|
| Yes | 34 (73.9%) |
| No  | 12 (26.1%) |

Comments Question 9 (30 in total – see appendix f)

### Self-reported health status of carer (Q10)

|                | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------------|-----------|---------|---------------|--------------------|
| Very good      | 14        | 30.4    | 30.4          | 30.4               |
| Good           | 4         | 8.7     | 8.7           | 39.1               |
| Fair           | 5         | 10.9    | 10.9          | 50.0               |
| Poor           | 3         | 6.5     | 6.5           | 56.5               |
| Other          | 1         | 2.2     | 2.2           | 58.7               |
| Don't know     | 11        | 23.9    | 23.9          | 82.6               |
| Not applicable | 8         | 17.4    | 17.4          | 100.0              |
| Total          | 46        | 100.0   | 100.0         |                    |

## C: Preferred Place of Death

### Patient (Q11)

|          | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------|-----------|---------|---------------|--------------------|
| Home     | 26        | 56.5    | 56.5          | 56.5               |
| Hospital | 2         | 4.3     | 4.3           | 60.9               |
| Other    | 1         | 2.2     | 2.2           | 63.0               |
| Hospice  | 17        | 37.0    | 37.0          | 100.0              |
| Total    | 46        | 100.0   | 100.0         |                    |

Patient with stated preference of 'other': health records reviewed and preferred place of death hospital.

**Carer (Q12)**

|                | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------------|-----------|---------|---------------|--------------------|
| Home           | 19        | 41.3    | 41.3          | 41.3               |
| Hospital       | 1         | 2.2     | 2.2           | 43.5               |
| Don't know     | 1         |         | 2.2           | 45.7               |
| Not applicable | 14        |         | 30.4          | 76.1               |
| Hospice        | 11        |         | 23.9          | 100.0              |
| Total          | 46        |         | 100.0         |                    |

**D: After patient's death (completed by 41 respondents)****Actual Place of death (Q14)**

|              | Frequency | Percent | Valid Percent | Cumulative Percent |
|--------------|-----------|---------|---------------|--------------------|
| Home         | 8         | 17.4    | 19.5          | 19.5               |
| Hospital     | 6         | 13.0    | 14.6          | 34.1               |
| Nursing Home | 3         | 6.5     | 7.3           | 41.5               |
| Hospice      | 24        | 52.2    | 58.5          | 100.00             |
| Total        | 41        | 89.1    | 100.0         |                    |
| Remain Alive | 5         | 10.9    |               |                    |
| Total        | 46        | 100.0   |               |                    |

These five remained living when the study closed.

**Was death expected? (Q15)**

|             | Number (%) | % out of 41 patients |
|-------------|------------|----------------------|
| Yes         | 34 (73.9%) | 82.9                 |
| No          | 6 (13.0%)  | 14.6                 |
| Don't know  | 1 (2.2%)   | 2.4                  |
| No response | 5 (10.9%)  |                      |

**If the patient died at home, which of the following services were being used by the patient? (Q16)**

|                          | Number (% out of 8 patients) |
|--------------------------|------------------------------|
| Social Services          | 5 (%)                        |
| Healthcare funded carers | 4 (50%)                      |
| End of Life              | 8 (100%)                     |
| SPCS Support             | 8 (100%)                     |
| Primary Care Team        | 8 (100%)                     |
| Other                    | 1 (%)                        |

**If the patient died in hospital, which of the following agencies were involved? (Q17)**

|                        | <b>Number (% out of 6 patients)</b> |
|------------------------|-------------------------------------|
| SPCS                   | 3 (50%)                             |
| Specialist CNS         | 3 (50%)                             |
| Discharge Liaison Team | 6 (100%)                            |
| Other                  | 3 (50%)                             |

**Use of pathways (Q18)**

|                                      | <b>Number (% out of 41 patients)</b> |
|--------------------------------------|--------------------------------------|
| LCP                                  | 24 (58.5%)                           |
| GSF                                  | 35 (85.4%)                           |
| Personal held record "Yellow Folder" | 19 (46.3%)                           |
| Devon Docs Special Message Form      | 13 (31.7%)                           |

18 (39.1%) made comments (Q19) and no demographic details had changed from A or B (Q20).

Appendix f)

**DATA SHEET COMMENTS**

PPOC = Preferred place of care

APOD = Actual place of care

**Question 8 - Comments living arrangements**

| Patient No | Achieved PPOC | APOD     | Comments                           |
|------------|---------------|----------|------------------------------------|
|            | No            | Hospital | Main carer does not live in house. |

**Question 9 - Could end of life be provided in the patient's home?**

| Patient No | Achieved PPOC | APOD     | Comments  |
|------------|---------------|----------|---|
|            | Yes           | Hospice  | Challenging as lives alone. Family to move in   |
|            | Yes           | Hospice  | -   |
|            | No            | Hospice  | With right amount of care   |
|            | Yes           | Hospital | Physically yes with support services  |
|            | No            | Home     | Stair lift in situ If enough support services available<br>Was given opportunity for discharge – opted for acute care.          |
|            | No            | Hospice  | Challenging a mobile home but potentially possible  |
|            | Yes           | Home     | If adequate help available – would need much support  |
|            | No RH         | N/H      | Lives with brother who is not well<br>Would need vast amount of care and support  |
|            | Alive         |          | Difficult lives alone. Possible if children moved in  |
|            | No            | Hospice  | No two young children in the house  |
|            | Alive         |          | Challenging as lives alone  |
|            | No            | Hospice  | Need support – elderly wife   |
|            | No            | Hospice  | Alone so would be very difficult  |
|            | Yes           | Hospice  | Challenging because alone at home. family may help out for a few days   |
|            | Yes           | Hospice  | Would prefer to be at home but wife would not cope when care needed<br>Does not wish wife to be involved too frail and confused |
|            | Yes           | Hospice  | Very difficult because psychologically complex. Family but no carers.   |
|            | Alive         |          | As long as can cope   |
|            | No            | N/H      | Only with increased family support  |
|            | Yes           | Hospice  | But very challenging, not central heating patients live nearby but elderly  |
|            | No            | N/H      | Patient lives alone in one bed home, does not want to be a burden   |
|            | Yes           | Hospice  | Lives alone would be possible only if 24 hr care available  |
|            | No            | Hospital | Lives in N/H  |
|            | Yes           | Hospice  | Very difficult because lives with elderly parents whom patient was caring for.  |
|            | No            | Hospital | Would need considerable support   |
|            | No            | Home     |   |
|            | Yes           | Hospital | Patient does not wish to die at home  |
|            | No            | Hospice  | If elderly husband can manage it  |
|            | Yes           | Hospice  | Very difficult lives alone  |

**Question 11** - Comments on patients preferred place of death

| Patient No | Achieved PPOC | APOD    | Comments  |
|------------|---------------|---------|---|
|            | No            | Hospice | With right amount of care<br>Adamant she wants to stay at home, if husbands becomes ill would like to share a bed and both be cared for at home |
|            | Yes           | Home    | Worries about his wife coping, so would be happy to go to Rowcroft  |
|            | No            | Hospice | But hospice if becomes difficult to manage  |
|            | No            | Hospice | If husband can manage as she becomes more poorly  |
|            | Alive         |         | If symptom control difficult - hospice  |

**Question 12** - Comments Carer preferred place of death

| Patient No | Achieved PPOC | APOD    | Comments  |
|------------|---------------|---------|---|
|            | Yes           | Home    | (Carer was) not sure depends whether she can manage |
|            | No            | Hospice | No Carer  |
|            | No            | Hospice | As long as husband can cope                         |

**Question 16** - Which services were used?

| Patient No | Achieved PPOC | APOD | Comments  |
|------------|---------------|------|---|
|            | Yes           | Home | 2 x night shifts<br>Sisters come down to help<br>GP very good regular visitor |

**Question 19** - Any other comments

| Patient No | Achieved PPOC | APOD     | Comments  |
|------------|---------------|----------|---|
|            | No            | Hospice  | Professional thoughts – could not be managed at home –paranoid agitated. Husband requested admission. |
|            | Yes           | Home     | Sisters come down to help   |
|            | No            | Hospice  | Not sure whether death expected   |
|            | Yes           | Home     | Exemplary GP support  |
|            | No            | Hospice  | Husband prompted admission  |
|            | No            | Hospital | Family present daughter involved in care. Peaceful.   |
|            | Yes           | Home     | Message to Devon docs do not admit to hosp  |
|            | Yes           | Home     | Very supportive x stayed at night – no carer  |
|            | No            | Home     | Very peaceful death   |
|            | Yes           | Home     | Peaceful.<br>Good family and professional support   |
|            | No Res Home   | N/H      | Death not expected  |
|            | Yes           | Hospice  | Symptom control an issue  |
|            | No            | Hospice  | Definite change of mind   |
|            | Yes           | Hospice  | Does not with wife to be involved too frail and confused<br>Deteriorated prior to discharge to N/H    |
|            | No            | Hospital | Appropriate place of death  |
|            | Yes           | Hospice  | Appropriate place of care   |
|            | No            | Hospital | Patient actual preferred place of care was N/H hospice if symptoms difficult to control               |
|            | No            | Hospice  | Professional thought hospice was Preferred place of care had discussed at length with family.         |