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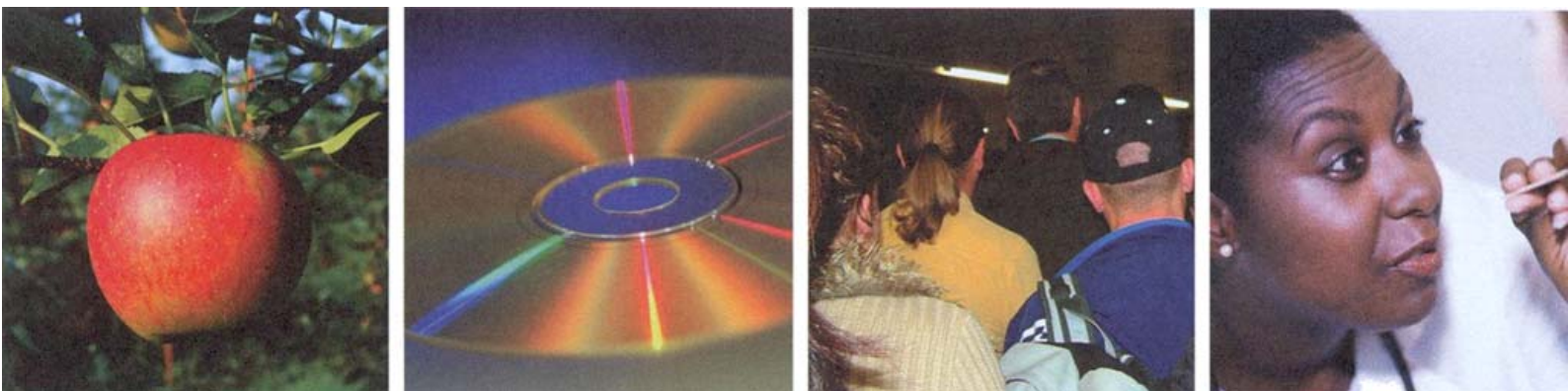
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# Developing a Patient Preference Questionnaire for Place of Care When Dying

Phase 1 – Hospices



**Laura Holdsworth & Annette King**

**Centre for Health Services Studies  
University of Kent**

**August 2009**

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Centre for Health Service Studies  
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Commissioned by:  
Sheila Pitt, Head of Cancer, Long Term  
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# Executive Summary

## Background

1. Meeting patient preferences for care at the end of life is a cornerstone of the Department of Health's *End of Life Care Strategy* (2008). However, evaluating a service's impact on meeting these preferences depends upon its ability to understand and monitor patient preferences. The collection of patient preferences is patchy and reasons for this are not well understood. The literature indicates a number of potential staff issues for obtaining preferences which may inhibit routine collection. These include: not knowing what to ask of patients, inadequate confidence and communication skills, and lack of prior knowledge about the patient.

## Aims and Objectives

2. The aim of this study was to develop a staff toolkit for obtaining preferences for place of care and death with palliative care patients. The toolkit was to include guidance and a set of questions acceptable to patients, carers and staff. The objectives were to:
  1. Identify issues for collecting preferences from both the perspective of service users (patients and carers) and hospice staff.
  2. Create a questionnaire for collecting preferences on place of care and death to be used by hospice staff.

## Methods

3. A search of the literature to identify existing questionnaires and previous work on eliciting preferences was carried out. Focus groups and interviews with hospice staff, patients, carers and bereaved carers were used to identify local issues. A questionnaire was then created for hospice staff to use to improve recording rates of preferences which included tick boxes for ease of use and room to record important information about the conversation. The questionnaire was then piloted by hospice Community Nurse Specialists with new referrals to the hospice.

## Findings

The following section represents the combined findings from the three stages of the project.

4. The timing of discussions must be sensitive to patient needs, which may conflict with the hospice's time requirements to plan service provision, particularly for home care. The needs of the hospice services are not often considered by patients, however having an open discussion about the service's limitations for forward planning can be a useful and acceptable way of discussing death with patients and carers.



5. Some patients and carers stated that it would be easier to talk about their preferences if they were warned in advance that they would be asked. This prefacing information about staff expectations could be given during a telephone call to arrange the appointment, or during the first visit in preparation for the next. There is a potential opportunity here for better coordination between the referring doctor and the hospice so that patients come to the hospice with as much information as possible.
6. It is important for hospice staff to build relationships with patients and carers and this can make it easier to talk about death. A healthcare professional or having the conversation in the right context can improve the likelihood that patients will be open to end of life discussions, such as a doctor bringing it up on an initial assessment when explaining the various services available.
7. The main contradiction in what staff and service users said was whether or not they had been asked about their preferred place of death; most patients and carers had said they had not been asked, though staff said they asked about 90% of the time. We did not explore the reason for this discrepancy. Perhaps keeping written records in the patients' homes would help to enable patients and carers to understand when they have expressed a preference as it may be ethically questionable to record and act on a preference if the patient is not aware of it.
8. Some of the bereaved carers expressed concerns over whether the decisions they made for their relative when they were incapacitated were in line with the patient's wishes. Having no written record or explicit forward planning left the bereaved carers feeling uncertain. Staff facilitation of discussions on preferences between patient and carer may be essential in helping improve bereavement outcomes.

## Conclusion

9. Recording patient preferences is not straightforward; it requires staff to feel confident in their role and relationship with the patient and involves skills to recognise possible opportunities to open the discussion.
10. Recording preferences should be standardised: staff should use the same language, timing, and criteria for asking about preferences. This will help ensure that choices are clear to all involved that decisions are not taken because of a lack of options.
11. Being open and honest about the choices that must be made at the end of life can help people feel more in control of their situation which may in turn improve bereavement outcomes.
12. While some patients will never want to discuss their preferences, others who have difficulty with it will open up given the right opportunity and support from healthcare professionals.

# 1 Introduction

Meeting patient preferences for care at the end of life is a cornerstone of the Department of Health's *End of Life Care Strategy* (2008). However, evaluating a service's impact on meeting these preferences depends upon its ability to understand and monitor patient preferences. The collection of patient preferences is patchy and reasons for this are not well understood. The literature (Murtagh and Thorns, 2006; Munday *et al*, 2009) indicates a number of potential staff issues for obtaining preferences which may inhibit routine collection. These include: not knowing what to ask of patients, inadequate confidence and communication skills, and lack of prior knowledge about the patient.

There is little evidence in the literature on best practice for collecting patient preferences on place of care and death. There have been studies on developing questionnaires for creating advance directives, but little on how and when to explicitly identify place of death preferences. Previous studies have looked at preferences for end of life care, including place (Higginson, 2003), but these assume that preferences for place of care are the same as preferences for place of death. Many studies use healthy respondents rather than patients with life limiting conditions to help develop questionnaires and provide indicators of preference which means they may not accurately represent the issues of patients at the end of life.

The need for a systematic method of collecting patient preferences is necessary in order to ensure that services are meeting these preferences. A good questionnaire for collecting preferences and specialised staff training should ensure that preferences are collected routinely and accurately.

The protocol for the study was sent to the East Kent Research Ethics Service for advice on submission requirements, but did not fall within their remit as it did not involve NHS patients or staff. Therefore the study was submitted to the School for Social Policy, Sociology, and Social Research Ethics Committee at the University of Kent from which it received ethical approval.

## 2 Aims and Objectives

The aim of this study was to develop a staff toolkit for obtaining preferences for place of care and death with palliative care patients. The toolkit was to include guidance and a set of questions acceptable to patients, carers and staff. The objectives were to:

1. Identify issues for collecting preferences from both the perspective of service users (patients and carers) and hospice staff.
2. Create a questionnaire to be used by hospice staff for collecting preferences on place of care and death.

### 3 Methodology

The study was conducted in three stages. Stage 1 comprised a literature review for questionnaires and training for healthcare professionals for asking about preferences on place of death. The databases of Medline, CINAHL, and EMBASE were searched using combinations of the following terms: death, die, dying, terminally ill, terminal care, palliative care, cancer mortality, cancer patient, hospice care, hospices, hospice patients, home health care, attitude to death, questionnaire, research instruments, proforma, tool, toolkit, instrument, approach, advance care planning, advance directive, living wills, patient decision making, preference, choice, patient satisfaction, and focus group (Appendix 1). Abstracts which matched the search terms were then analysed for relevance and full articles were retrieved if they met the following criteria:

1. described a toolkit, questionnaire, or other recordkeeping method for collecting preferences on place of death, AND/OR;
2. described training for healthcare professionals to help patients make decisions, build staff confidence, or improve professional skills for asking preferences.

The aim of the literature review was to identify any existing tools which would be suitable for use, or if not, how one could be developed. Fifteen articles out of 191 matched our criteria and were retrieved and reviewed. After further scrutiny nine were deemed relevant and useful for this review.

In stage 2 focus groups were conducted separately with Community Nurse Specialists (CNSs), patients, carers and bereaved carers. Table 1 shows the number and range of participants in each group. Participants for the focus groups were recruited by participating CNSs at all three hospices. Patients were recruited if they had a life-limiting illness (defined as a life expectancy of less than 12 months). Carers were recruited if they cared for a patient who was known to the hospice and had a life-limiting condition. Bereaved carers were identified by both the CNSs and hospice counsellors. Hospice staff first approached potential participants and gave them an information sheet and short verbal explanation of the project. Staff had to be sensitive in their recruitment approach and therefore only approached people if they felt they would be able to cope with the discussion. If the potential participant agreed to participate their details were then passed to the research team. A researcher then called each participant a few days before the focus group to confirm their interest. During the phone call the potential participant was given the opportunity to ask additional questions or withdraw.

Table 1. Recruitment rate and description of participants by group

Group	Total number recruited	Total enrolled participants (rate)	Group identifier (participants in group)	Gender		Age distribution			
				M	F	18-45	46-55	56-65	66+
Staff	6	6	S-A (6)	2	4	---	---	---	---
Patients	16	5 (31%)	P-A (1) P-B(2) P-C(2)	2*	3	0	1	0	3
Carers	13	5 (38%)	C-A (5)	3	2	1	1	2	1
Bereaved Carers	8	5 (63%)	B-A (1) B-B (4)	1	4	0	0	3	2

\* Age data missing for one participant.

There were 3 rounds of recruitment for patient participants.

As expected, recruitment amongst all groups except staff was quite difficult. The CNSs from all three Pilgrims Hospice sites (Canterbury, Thanet, Ashford) were asked to recruit suitable participants from their current caseloads. The aim was to recruit 12 participants to each group with the expectation that only 50% would arrive on the day due to changes in health. The ideal number of participants in a focus group is between 6 and 10 (Morgan, 1997), but due to the sensitive subject matter it was deemed that smaller groups (4-6) would be more appropriate. Small focus groups of less than 4 people were also used in another study to good effect (Barnes *et al*, 2007). However, it was difficult for staff to identify 12 suitable participants. This may have been because staff felt protective of their patients and chose not to ask certain patients rather than presenting them with the option and allowing them to refuse. Some patients became too unwell to attend in the time between recruitment and the focus group, which was only 2 to 3 weeks. Patient deterioration also had an effect on carer recruitment as carers would not come if their relative was unwell on the day.

The focus group interview schedules (Appendix 2) were semi-structured and focus groups were facilitated by two researchers. Topics for the staff focus group covered: how often preferences are recorded, how staff feel about discussing dying with patients and their families, how they decide to initiate the discussion, and what can be done so they feel more comfortable having the discussion. For the service user groups the following issues were discussed: how decisions are made, how they interpret a place of care versus a place of death or dying, how they feel about discussing death with family and healthcare professionals, how important it is to have preferences recorded, and how hospice staff can sensitively discuss death. The focus group discussions were transcribed and analysed thematically (Liamputtong and Ezzy, 2005). Themes and issues were validated by group-to-group analysis (Morgan, 1997).

A mixed focus group of patients, carers, bereaved carers and CNSs was planned to take place after all of the focus groups had been completed. However after completing the individual groups we decided against this for a number of reasons. It became clear in the focus group with bereaved carers that some of their experiences were emotionally challenging and maybe upsetting for patients and current carers. As the discussions were

often emotional the CNSs may have felt pressured to play a counselling role which would conflict with having an objective group discussion. Generally, there was good agreement among the service user groups, though there were some contrasts with feedback from staff. In light of these observations the researchers decided against a mixed focus group. Instead the research team arranged a second session with the CNSs to present the findings from the service user groups and worked towards developing the questionnaire together.

The findings from the literature review and focus groups were then combined to create a toolkit composed of the questionnaire and guidance for using it.

The questionnaire was piloted in Stage 3. The researcher explained how to complete the questionnaire and gave instructions for the pilot after the second session with the six CNSs. The CNSs were asked to pilot the questionnaire with new referrals to the hospice. At the end of the three week piloting period, four of the CNSs met with the researcher to provide feedback on using the questionnaire and whether any changes should be made. The four CNSs were able to pilot the questionnaire a total of 17 times. They were asked to bring anonymised copies of the entries that they had made. Two of the CNSs were unable to attend the final follow-up meeting.

Participants in the service user focus groups were asked to provide anonymised written feedback on the toolkit by post to ensure that it was accurate and representative of the issues that were discussed. Prior to sending out postal response forms, a researcher asked the hospice to notify her if there were any participants who it would not be appropriate to send a form to, e.g. if a patient had been admitted to hospice or had died. This was done so as not to distress any carers or relatives. Hospice staff said it would not be appropriate to send the form to three participants, but were not asked to elaborate as to why due to patient confidentiality.

## 4 Findings

The findings are presented from each of the three stages separately. All names of participants in quotes have been changed.

### 4.1 Stage 1 – Literature review

In considering how the literature could inform the development of the toolkit, information was funnelled into what could develop the questionnaire and what could be used for the training element. The findings from the literature review will briefly be summarised as it pertains to the development of the questionnaire or training. These themes reflect both the conclusions and recommendations made by authors as well as our own analysis of the literature. Though in this study focus groups were used, only one study (Barnes *et al*, 2007) found during the literature review used focus groups with palliative care patients. This is likely because recruitment can be quite difficult as participants are frail and mortality is

high. Most studies used one to one interviews, a group of experts, or literature review to aid questionnaire development.

#### 4.1.1 Questionnaire

Articles from the literature review were chosen based on whether they contained practical or theoretical evidence and advice for creating a questionnaire. They were also chosen if they contained useful ideas for developing the training element, though this will be discussed separately. Articles were particularly useful if they contained concrete examples of wordings for questions or topics for healthcare staff training.

There are very few questionnaires which specifically address preferences around dying. Only two samples of questionnaires were found in the literature review (Borreani *et al*, 2008; Murtagh and Thorns, 2006). Both sought information on similar topics, such as patient's desire for information and choices for care and treatment. The Borreani *et al* tool is very thorough and specific, with questions such as 'What kind of mood/atmosphere would you like to have all around you at the moment of death?', whereas Murtagh and Thorns questionnaire is general and serves more to facilitate a discussion rather than seeking specific pieces of information.

The development of this questionnaire sought to build on existing knowledge and refine it for meeting the requirements of Pilgrims Hospices. Five themes were identified from the literature as useful in guiding the development of the questionnaire.

*Involving others:* Patients should be given an opportunity to choose who they want present when discussing their preferences for care and dying (Conroy *et al*, 2009).

*Informational needs:* Patients should be able to decide how much information they want to receive about their condition (Huggins and Brooks, 2007; Murtagh and Thorns, 2006).

*Stepped approach:* Questionnaires should be structured so that they move from easier, less invasive questions to the more difficult and emotional questions (Barnes *et al*, 2007). Questions should follow a logical order of progression from the patient's understanding of their prognosis, to choices for care, and then to choices around resuscitation and dying. Each of the different topic areas can have a screening question for assessing whether the patient wants to continue with the questions or stop (Borreani *et al*, 2008). They should be given the opportunity to end the discussion at any time or only answer those questions that they are willing to discuss.

*Wording:* 'Place of care' and 'place of death' are not synonymous to all patients and therefore healthcare professionals should not assume that 'place of care' is a euphemism for 'place of death' (Agar *et al*, 2008).

*Organisation of the questionnaire:* There should be room for the healthcare professional to write observation notes about their discussion with the patient (Borreani *et al*, 2008).

### 4.1.2 Training

Training for healthcare professionals was another element highlighted in the literature as important for eliciting patient preferences. Four themes were identified that could be included in a training element of how to administer the questionnaire and general guidance for using it.

*Timing:* The timing of when advance care planning questions are asked is important. Advance care planning questions should not be asked during a major life event, such as moving into a care home, as this may increase stress levels (Barnes *et al*, 2007). Questions should only be asked once the patient has an understanding of their prognosis (Borreani *et al*, 2008). Discussions should also continue over time and be ongoing as preferences may change as the patient's condition deteriorates (Conroy *et al*, 2009; Huggins and Brooks, 2007).

*Professional judgement:* Healthcare professionals should aim to use a consistent set of criteria when judging whether or not to ask patients about their preferences. Rather than making assumptions about a patient's readiness to discuss their preferences, they should try to offer the discussion and allow patients to tell them when they do not wish to discuss further.

*Prior information:* Patients may be more likely to engage in creating an advance care plan if they have prior information regarding its purpose and importance. Patients need education regarding the importance of making plans for their future care (Schickedanz *et al*, 2009).

*Patient-medic relationship:* Discussions about a patient's end of life preferences are more likely to be successful if they are held with a healthcare professional who has an established, trusting relationship with the patient (Conroy *et al*, 2009; Huggins and Brooks, 2007; Munday *et al*, 2009).

### 4.1.3 Assessment of the literature

Apparent in the literature was a need for healthcare staff training and equally education for the patient on the relevance and importance of voicing their wishes. Patients' reluctance to discuss preferences could potentially be overcome with increased information from the healthcare professional on the impact that their preferences have on the care they receive. The literature did identify a number of barriers which may inhibit discussions on care at the end of life, such as not knowing when to initiate the discussion and using language which can be confusing to the patient. These barriers were able to be incorporated as guidance in the toolkit, though some of the barriers relating to professional practice will take time to become imbedded in practice.

There is little practical guidance in the literature on developing a questionnaire for identifying patient preferences at the end of life, particularly with hospice patients. Much of what has been done has involved one to one interviews or healthcare professionals testing a tool or pathway without directly consulting patients on how the questionnaire should be structured. Worryingly, less than half of the studies found had actually been conducted with

input from end of life patients (Agar *et al*, 2008; Barnes *et al*, 2007; Borreani *et al*, 2008; Murtagh and Thorns, 2006). This fact calls into question the patient-centeredness of questionnaires which have not been developed in cooperation with the target patient group. Research on the healthcare professional perspectives, while valuable, may not accurately reflect the patient experience.

## 4.2 Stage 2 – Focus groups and toolkit development

### 4.2.1 Focus group findings

The first focus group was conducted with staff so that any specific issues they raised could be built into the interview schedules for the user groups. The purpose of the hospice staff focus group was to identify the issues they face in discussing and recording patient preferences. The aim of the service user focus groups (patients, carers, and bereaved carers) was to look at the questionnaire from the service user perspective and identify service user issues in talking about end of life preferences and how they feel about discussing dying with staff. The findings from the staff and service user groups will be presented separately.

#### *Pilgrims Hospice Staff – Community Nurse Specialists (CNS)*

##### *How often do you record preferences?*

The CNSs reported that they record something for the question ‘does the patient have a preferred place of care when they are dying?’ approximately 90% of the time<sup>1</sup>. According to the CNSs this figure would include all responses, even when CNSs record that the patient did not wish to discuss their preferences. The CNSs said that they do not always record a preferred place of death in the Patient Profile Preference Questionnaire, but may use case notes or the Bereavement Risk Assessment form instead. They said that there are some patients with whom discussing items on the form are not appropriate, such as if they are in denial about their illness. In such cases CNSs do not attempt the discussion, but they would normally indicate this on the form. Two of the CNSs were adamant that they would not discuss preferences on the first visit as they thought it would be inappropriate since they did not know the person well enough. This type of sentiment will not likely be changed through a toolkit, but will require more focussed professional training.

##### *How do you complete the questionnaire?*

There was some variability in how the CNSs completed the questionnaire. Some take it with them to the patient’s home and complete it while sitting with the patient. Others prefer to spend their time chatting with the patient and then fill in the form after the meeting. There were also differences in how staff chose to initiate the discussion about preferred place of death. One CNS would look for opportunities to open the discussion, such as saying ‘Though

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<sup>1</sup> This is percentage is based on the CNSs recollection, but we do not have data to verify if this is accurate.



you are quite well now, have you thought about the future?', whereas another CNS would prefer to wait for cues from the patient to have the conversation. In particular staff enthusiasm for information seeking seemed to reflect the value they placed on the various pieces of information the questionnaire asked for. For example one CNS thought the question 'Does the patient carry a donor card?' was not particularly important and therefore did not seek out that information from the patient. All said that they do not go through the questionnaire question by question, but rather use it to remind them what issues they need to discuss. The CNSs seemed to prefer to rely on their professional expertise to help elicit information rather than use the questionnaire. The wide variety of professional practice in completing the questionnaire could lead to data being unreliable.

#### *How can the questionnaire be improved?*

Though staff were generally happy with the current form, they did have specific ideas for how the form might be improved. They suggested having prompts for when to review the form with the patient. They wanted to ensure that the form is flexible, that answers could be changed at any time and therefore suggested having room to write a date for when the preference was recorded.

The CNSs did not want the questions on the questionnaire posed as questions to the patient, such as 'What is your understanding of your diagnosis and prognosis?' They preferred that it stay as questions to staff, 'What is the patient's understanding of their diagnosis and prognosis?', which would allow staff to discuss the questions in a way that they felt was appropriate. This style of questioning conflicts with the two examples from the literature which pose questions to the patient rather than staff (Borreani *et al*, 2008; Murtagh and Thorns, 2006). There does not appear to be any evidence to suggest that one style of questionnaire is more effective at eliciting response than the other, but the comments suggest that hospice staff are more comfortable asking questions in their own way.

#### *Patients, Carers and Bereaved Carers (service user groups)*

There was a general consensus among the patient, carer and bereaved carer groups on several issues. Participants agreed that 'place of death' was an unpalatable term; a more acceptable term was 'place of dying'.

#### *Have you been asked your preferences?*

Most participants said that they had not been asked their preference for place of dying directly by hospice staff. However, some said at the time that they were not ready to have this discussion with hospice staff and therefore did not want to be asked. Almost all participants said that the hospice's approach to them had been appropriate which suggests that the hospice may have made certain judgements about preferred care without the patient or carer being explicitly informed. One carer said that he believed that the hospice could give guidance to help make decisions, but that ultimately it is up to the patient and carer to make those decisions:

*Carer 1: I think one important thing is that the professional, that third party, must not be seen to be making decisions on your behalf.*

*Carer 2: No, I agree.*

*Carer 1: And that's their talent and some are good at it and some aren't... If you go into these meetings or whatever and you're getting the impression that they're making decisions for you they're doing their job wrong. And that's part of the education for the professional I think. You've got to come to the decision, and they can give you options and they can give you guidance, and they can give you sort of case lore to think about, but at the end of the day you've got to say.*

One patient said that she was reluctant to have her wishes written down because it meant admitting to herself that she would die:

*Facilitator: Is there any reason why you wouldn't [want to have a written record from the hospice]?*

*Patient: I think the finality of it.... proof that you've been discussing it, you know, it becomes black and white.*

However, several carers and patients said they wanted their preferences written down because they believed it was a way to ensure that the hospice did everything possible to meet their wishes. One carer wanted to have a copy of his stated preferences so he could feel more in control, though most other carers and patients did not mind if they had a copy or not so long as the hospice knew what they wanted.

*Who should ask your preference?*

Carers agreed that they should be asked at some point about their preferred place of dying for their relative. There was some initial disagreement among the patient groups with some stating that it is OK for nurses to initiate the discussion and others stating that it is up to the patient to come forward when they are ready to discuss. However, by the end of the discussion they did say that the subject of death could be initiated by staff if it was done in the context of explaining services provided by the hospice. All agreed that it is important for the hospice to know their wishes in order for them to be fulfilled. Both carers and bereaved carers agreed that if the patient is not ready to discuss it with staff then the carer may be a good person to initiate the discussion with the patient, but only if they are willing to discuss it themselves.

*When should you be asked your preference?*

For those who attended the day hospice, most said that the first meeting with hospice staff is not an appropriate time to ask about preferences on dying as they may still be rather positive about their prognosis and not want to consider the possibility of death. Some participants said that discussing death on the first meeting could damage the relationship between the patient and healthcare professional. However, others said that the first meeting would be appropriate if it was discussed in the context of what services the hospice can provide. Most agreed that it could be mentioned in the first meeting, but then left with

the patient to consider and then discuss later. When death is imminent, most patients said that the discussion on preferences is relevant and should be initiated, though waiting until this point to ask may not be feasible from a service provider viewpoint.

After one of the focus groups two patients and the facilitators were discussing more general issues about how the hospice plans service provision and national policies on end of life care. During this discussion the patients who said they had not yet discussed their preferences with the hospice because they were not ready, stated that after having this discussion they would be ready to discuss place of dying with hospice staff should they ask now. This was an unintended outcome, but does show that people who do not feel ready to discuss death can be enabled to express their wishes in the right context. The more general discussion on service planning seemed to prompt the patients to think about some pragmatic aspects of their care and the need for planning ahead in order to enable the service to meet their wishes.

The bereaved carers largely said that they lacked information on the dying process. This was particularly upsetting for them as they believed that more information on what to expect in the final weeks and days would have made coping a bit easier. In particular one bereaved carer whose relative died in the hospice expressed uncertainty whether that was the right decision. In his final days she was unable to find out from him what he wanted and made the decision to admit him to the hospice. In the end she felt this was the right decision. For the one bereaved caregiver who was certain of his wife's wishes he expressed no doubts or regrets over how she spent her final days.

Participants who had used day hospice services in all three groups voiced strong concerns about the stigma which surrounds hospices; that hospices are a place of death and dying. They had all expressed initial reservations about accepting help from the hospice because of this perception. One patient explained his first experience with the hospice and how he did not want help from the hospice because of his perception of its role:

*The pain that I was in was excruciating and Doris rung the local doctor ... So the doctor said increase his opiates ... The doctor rung back and said I'm going to get the pain control team to him. Then the phone rung again and [it was a lady from the hospice]. And no one had said to Doris or anybody, and this is where the problem starts ... people do not understand what the day hospice is. And Doris, when she answered she said to the woman, she said it's no good you coming here, she said he won't see you... Doris said look let's not beat about the bush, she said I know what you're trying to do, but I also know what my husband is like and he's not going to accept that he needs the hospice yet, and she responded very quickly and said no, we realise that. So Doris said well why on earth doesn't somebody make that plain to the general public that you're not the end of the story? And that is the real problem ...It's most important that people realise... it's not the beginning of the end.*

Many patients expressed the sentiment that hospices are 'not the end', meaning a referral to the hospice is not a death sentence.

### *4.2.2 Toolkit development*

Whilst most of the literature recommended that a more structured questionnaire should be used, the findings from the focus groups suggested that it is best to let professionals use their expertise to facilitate a discussion on dying. The hospice is in a unique position for care delivery in that staff are enabled to form relationships with patients. Also hospice staff deal with death daily and so may have felt more comfortable discussing death than would more general practice staff. Therefore using a structured questionnaire in which questions are spelled out in full was not deemed to be appropriate. A structured questionnaire may be more appropriate in situations where healthcare professionals are not able to build such relationships or who are not comfortable with this type of questioning. Therefore no major revisions were made to the questionnaire<sup>2</sup> used by the hospice as it appeared that in the last hospice audit recording rates had improved to a sufficient level for conducting an audit on preferred place of death. However, for an audit the timing of asking the questions is important and therefore this is what was focused on. Also included in the toolkit was guidance on the importance of collecting preferences and how best to have discussions with patients who seem reluctant.

### *4.2.3 Reflections on Stage 2*

Some staff viewed gathering patient preferences as a high priority for delivering a patient centred care plan and therefore had many strategies for facilitating the conversation. However some said that often other care needs, such as symptom control, should take precedence and therefore did not actively seek preferences unless the patient gave them cues that it was all right to discuss it. These different opinions seemed to reflect how they viewed the first assessment meeting with the patient; whether it is an opportunity to gather as much information as possible, or to let the patient guide the assessment process. Indeed staff who took the latter approach seemed to regard using different methods to gather preferences, as in the first scenario, as unacceptable. It would be useful to collect data on which technique is more effective so that staff can be trained in methods to consistently identify preferences.

The service user groups highlighted the complexity of discussing preferences. Though all participants said they were open to discussing death at some point, they had their own euphemisms for 'death' and seemed to balance between accepting death and still having hope for the future. The CNSs said that some patients come for non-end of life care, such as symptom control, but that the majority of patients they see are nearing the end of their life. However, from the patient point of view they expressed on a number of occasions that the hospice 'is not the end'; meaning that a referral to the hospice does not mean that death is imminent. This view perhaps suggests that they do not believe they are end of life patients even though the hospice may have a different view. It is understandable that the hospice does not want to destroy hope, but at the same time they should encourage patients to consider what will happen when they are dying which may help patients to voice their wishes at an earlier stage in their illness.

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<sup>2</sup> The questionnaire used by the hospice was adapted from the questionnaire developed by Murtagh and Thorns (2006).

The focus group findings suggest that clearer guidance for professional practice is needed for addressing patient preferences. If it is not clear how healthcare professionals should address preferences then there is the danger that they will rely on their own subjective judgements which could result in inconsistent discussions and misleading recordings of preferences. Therefore the toolkit aimed to provide guidance on when preferences should be discussed and tips for how the discussion could be brought up. It was also decided that the guidance given in the toolkit should also be explained verbally to reinforce the importance of asking about preferences.

### 4.3 Stage 3 – Piloting the questionnaire and toolkit

The CNSs piloted the questionnaire for three weeks with new referrals to the hospice. They were asked to bring their completed questionnaires from the pilot to the follow-up meeting. Table 2 shows the data that was recorded on preferred place of care when dying by the CNSs on the pilot questionnaires on the first visit only. The table shows the place that was preferred by the patient and carer (if available) and any other notes that were recorded. A preferred place of care was recorded in 10 of the 17 cases and 'home' was recorded 7 times (41%). In a previous short audit of community care, 'home' was preferred 6 times out of 15 patients (40%), therefore it appears that this pilot is consistent with a normal hospice caseload. In 8 cases the carer's preference was left blank, though this was only explained in one case (case 2).

Table 2. Preferred place of death and notes recorded by CNSs using the questionnaire during the pilot

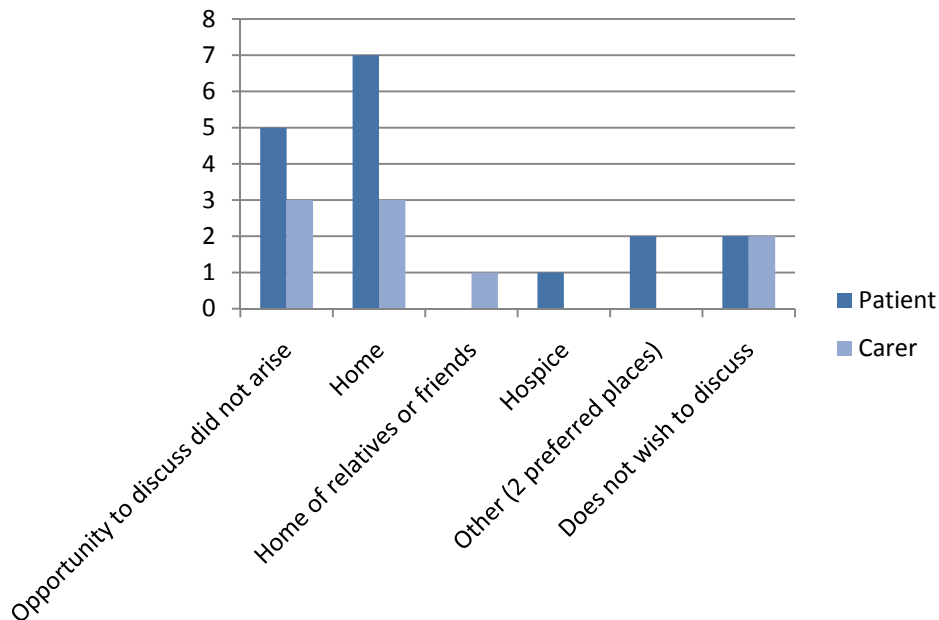
Case	Place of Death Preference		Notes written by the CNS
	Patient	Carer	
1	Home	Home	But if a burden to family would appreciate hospice admission
2	Home		Carer not present
3	Home	Home	
4	Home		
5	Does not wish to discuss		Does not recognise he will not get better
6	Home		
7	Home		
8	Opp. to discuss did not arise		Well and virtually asymptomatic
9	Home*	Home*	
10	Hospice	Does not wish to discuss	
11	Opp. to discuss did not arise		Patient focused on symptom control and proposed future palliative treatment
12	Other: Home of relatives or friends / Hospice	Opp. to discuss did not arise	Carer not present
13	Opp. to discuss did not arise	Opp. to discuss did not arise	Patient having further discussion with consultant re. further treatment
14	Opp. to discuss did not arise	Home of relatives or friends	Patient has Alzheimer's
15	Does not wish to discuss	Does not wish to discuss	
16	Opp. to discuss did not arise	Opp. to discuss did not arise	Symptom control and current care provision were the main focus
17	Other: Care home/hospice discussed as patient lives alone		Home is preferred place of care, not death. Patient referred to pal care services as progressive disease evident on scans

\*This patient's preference was recorded as 'care home', but upon discussion, their preference should have been recorded as 'home' as they were already living in a care home.

Chart 1 shows the same data as Table 1, but represented as a bar chart to show the total number of times each place was preferred by the patient and/or their carer. As mentioned above there is some data missing for carer's preferences and it is not clear as to whether a preference was not recorded because there is not a carer or they were not present, or because they chose not to express a preference. It is possible that the column for

'opportunity to discuss did not arise' may decrease after subsequent visits once the CNSs feel more comfortable with the patient and carer.

Chart 1. Distribution of patient and carer preferences by place



The CNSs agreed that the layout of the questionnaire worked well. They liked that they could tick a box to show that they had made an attempt to discuss preferences or explain why a preference was not recorded.

The CNSs said they often had 'if then' responses about preferences, such as 'I want to stay at home, but if I become a burden then I would prefer to die in the hospice.' These situations are accounted for under 'other' in which the CNS should write the 'if then' statement from the patient in the space provided.

There was some confusion over when to tick 'care home' as a preferred place of dying. 'Care home' should only be ticked if the patient is not currently living in a care home, but wishes to die there. If the patient already resides in a care home and wishes to stay there, then 'home' should be ticked as the care home is their home. Care homes have been included under 'home' in this instance as this better reflects the person's living situation as well as impact on service provision. If someone chooses to move from home to a care home to die then ticking 'care home' represents an impact on local service provision and resources. However, if the person is in the care home already and therefore their choice is 'home', then there is no increased need for a bed in a care home as they already occupy that space. It could be argued that the resources needed to maintain a person at home versus a care home are different and therefore ticking the box should represent the type of location and therefore the resources needed. However, in these cases ticking 'care home' would misrepresent the fact that these people die in the place that they call home. It has been indicated in the toolkit when CNSs should record a care home as 'home'.

There was also confusion over where a preferred place of care should be recorded as the questionnaire only asks for place of dying. It was agreed that preferred place of dying should be ticked, but if preferred place of care differs than this should be written in the blank space next to each entry. This occurred in one of the 17 cases in the pilot.

As seen in Table 2 additional notes were only recorded about half of the time. Notes on the patient's condition when asking about preferences may provide useful information about patterns in CNS discussions with patients. It was discussed whether there was a short-hand way that could quickly indicate to someone reviewing the notes what type of condition the patient was in. The CNSs discussed the possibility of adding in a numerical scale on the side of each entry, such as the Karnofsky score (Karnofsky and Burchenal, 1949) or the Eastern Cooperative Oncology Group (ECOG) scale (Oken *et al*, 1982), both of which rate functionality. The Karnofsky score ranks a person from 100=perfect health to 0=death and the ECOG grades a person's performance ability from 0=fully active to 5=dead. This was not included in the final questionnaire (Appendix 3) as this would need further scrutiny from the hospice medical team.

## 5 Discussion

This study reinforced a number of themes and findings from the literature. Firstly the timing of discussions on death in relation to both entry to the service and disease progression were important. As suggested in the literature, discussing place of death should not be raised during important transitions; in this case being referred to the hospice. For some patients, accepting help from the hospice was difficult enough and they did not want to be asked about their end of life preferences while coming to terms with a life-limiting prognosis. For others though, they accepted the role of the hospice and were more open to discussing preferences. The timing of discussions must be sensitive to patient needs, which may conflict with the hospice's time requirements to plan service provision, particularly for home care. The needs of the hospice services are not often considered by patients. However these findings suggest that having an open discussion about the service's limitations for forward planning can be a useful and acceptable way of discussing death with patients and carers.

Some patients and carers in the study stated that it would be easier to talk about their preferences if they were warned in advance that they would be asked. This prefacing information about staff expectations could be given during a telephone call to arrange the appointment, or during the first visit in preparation for the next. There is a potential opportunity here for better coordination between the referring doctor and the hospice. The hospice currently requires doctors to tell their patients their prognosis before referring them to the hospice. The hospice could also require referring doctors to tell patients what to expect from the hospice, e.g. that they will be asked questions about their wishes for care so that they have this information before the first meeting.



The CNSs, patients and carers agreed that it was important for hospice staff to build relationships with patients and carers and that this would make it easier to talk about death. Though ideally patients and carers would discuss it with someone with whom they have an established relationship, they did not see it as entirely necessary, but rather just a preference and a condition which would improve the likelihood of a response. Patients and carers said that a person with medical authority or having the conversation in the right context would suffice for initiating the discussion, such as a doctor bringing it up on an initial assessment when explaining the various services available. However, some of the CNSs seemed to feel that it was not appropriate to have end of life discussions without first establishing a relationship. There is some contradiction in how CNSs and service users view the necessity of the relationship and it may be that establishing the relationship is more of an issue for the CNSs than the patients.

The main contradiction in what staff and service users said is whether or not they had been asked about their preferred place of death. In looking at what staff have said, it is possible that staff usually ask, but that patients and carers forget, or that the asking was so subtle that they did not realise it. A previous study found that 60% of patients did not remember having an end of life discussion (Wright *et al*, 2008), and therefore it is likely that patients and carers simply do not remember the discussion. In any case, if a preference is recorded then patients and carers should be made aware that a choice has been recorded in case they wish to change it. Perhaps keeping written records in the patients' homes would help to enable patients and carers to understand when they have expressed a preference as it may be ethically questionable to record and act on a preference if the patient is not aware of it.

On the face of it, making preferences explicit may not be necessary as feedback from bereaved carers indicated that they thought the hospice's approach and care given was appropriate and they were generally satisfied. Even though they said that they were not asked their preference, the hospice staff may have intuited or known it anyway and therefore were able to meet their wishes, though this was not communicated to the carers. Some of the bereaved carers expressed concerns over whether the decisions they made for their relative when they were incapacitated were what they would have wanted. Having no written record or explicit forward planning left the bereaved carers feeling uncertain. Previous research (Wright *et al*, 2008) has shown that patients who do not have end of life discussions experience more aggressive end of life care which results in worse quality of life for the patient. Carer bereavement outcomes are affected by patient quality of life, and a worse quality of life for the patient can result in worse quality of life for the carer, more regret and a higher risk of developing a depressive disorder. Staff facilitation of discussions on preferences between patient and carer may be essential in helping improve bereavement outcomes.

If patients did not accept their prognosis or were not prepared to discuss end of life care issues then this was a barrier to initiating discussions on end of life care. The CNSs seemed quite opportunistic in their approach to discussing end of life preferences, either waiting for the patient to initiate the discussion or waiting until the patient's condition worsened. In order to identify whether staff are waiting for patients to deteriorate it would be useful to

have CNSs record the condition of the patient when asking. The current questionnaire asks for anecdotal information, but the questionnaire could be revised to include a more objective rating scale, such as the Karnofsky or ECOG scales as discussed previously. More specific data about the patient's condition could reveal patterns in both staff recording practices as well as how patient and carer preferences change during the course of their illness.

## 5.1 Limitations

This was a small scale study and therefore caution must be used when interpreting the results. The findings from this study reflect the views of a small sample of people receiving hospice services and may not be generalizable to other patient groups.

Most participants in the focus groups had connections with the day hospice, though only around 10% of all hospice patients attend day hospice. Day hospice users have a greater understanding of what services the hospice provides and have had a greater chance of forming relationships with staff. In most cases this has meant that they have chosen the hospice as their place of dying.

Participants were selected by CNSs for their likelihood to participate which was based both on their mental and physical state, therefore patient and carer participants represent a very specific group of hospice service user and thus the findings may not be generalizable to the whole population. In addition, the only people who are likely to have come to a focus group and talk about dying were those who are prepared to express a view and may have had some discussions already, though there were some patients who had not yet made a decision about their future care wishes and did not yet feel that the time had come to discuss it. Also the CNSs would likely not invite people who had a poor experience with the hospice nor would they be likely to attend. The piloting phase sought to represent the experiences of those who would not be likely to attend a focus group, even if their representation was through staff feedback.

## 5.2 Reflections on methodology

There are both ethical and practical challenges in engaging end of life patients in qualitative research and focus groups are not often used for research in end of life care. In this study we aimed to have approximately six participants per group, but the numbers per group ranged from 2 to 6 and there were two single participant interviews. As participants were recruited for group discussions we gave the option to participants to withdraw if only one participant agreed to the focus group. The one to one interviews with user group participants were intense for the participant. The one to one situation seemed to make them feel that they must respond to a question which they may have otherwise passed on in a group setting. Interviews with patients worked better when there were at least two participants present, especially if they knew each other and therefore could provide emotional support to each other and relieve some of the burden if they became emotional.

Larger focus groups were not particularly productive either. Participants were only able to respond to questions by drawing on their own experience; this often led to extended storytelling. While it is useful to have a background story on each participant, in larger groups people can have their own motivation and agenda for telling their story which is not always appropriate to the topics being discussed. Limiting the focus groups to 3 or 4 people who are familiar with each other can help reduce diverging, though in order to get a range of views it is necessary to have multiple focus groups. Having participants in a group who know each other is beneficial as they create a comfortable and relaxed atmosphere and provide emotional support to each other.

We found that discussions are best kept to no more than an hour as they are emotionally draining for both participants and facilitators. At times participants did become upset, but chose not to leave the discussion as they seemed to regard tearfulness as a normal part of having or caring for someone with a life-limiting condition. Time can be kept to a minimum if there are fewer participants.

The discussions gave participants a chance to share their experiences and have them validated by others which seemed to be cathartic for participants. The patient who had the one to one interview said that she would have liked to have had another patient present to hear their experience.

## 6 Conclusion

Recording patient preferences is not straightforward; it requires staff to feel confident in their role and relationship with the patient and involves skills to recognise possible opportunities to open the discussion. Patients and carers must also be enabled to express a preference, which for many involves overcoming the fear that admitting death means it is going to happen. Therefore reliably recording patient preferences at appropriate times in their illness and with enough lead time for service planning can be difficult.

Recording preferences should be standardised: staff should use the same language, timing, and criteria for asking about preferences. This will help ensure that choices are clear to all involved that decisions are not taken because of a lack of options. Though preferences may be discussed informally, they should be formalised at some point to ensure that patients and carers know what to expect from the hospice service, but it should be clear that choices can be changed at any time.

Being open and honest about the choices that must be made at the end of life can help people feel more in control of their situation which may in turn improve bereavement outcomes. Patients and carers should be enabled to take ownership of their care plan and be encouraged to tell staff when they want to change something as it should be seen as a living document. Staff should help patients to realise the importance of their preferences in affecting their care and patients should take responsibility for having made those choices.

While some patients will never want to discuss their preferences, others who have difficulty with it will open up given the right opportunity and support from healthcare professionals. Healthcare professionals should weigh up the patient's reluctance to discuss preferences against the consequences of not having a clear idea of what a patient wants in order to plan service provision. Giving up on the discussion too quickly could not only result in an unplanned and unwanted institutional death but also a more difficult bereavement period for carers and relatives.

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# Appendices

## Appendix 1 – Search Strategy

### CINAHL search 1

1. CINAHL; \*ADVANCE CARE PLANNING/; 100 results.
2. CINAHL; exp \*ADVANCE DIRECTIVES/; 2583 results.
3. CINAHL; exp \*HOME HEALTH CARE/; 16830 results.
4. CINAHL; \*HOSPICES/ OR \*HOSPICE PATIENTS/ OR \*HOSPICE CARE/; 3628 results.
5. CINAHL; \*LIVING WILLS/; 259 results.
6. CINAHL; \*PALLIATIVE CARE/; 7098 results.
7. CINAHL; \*PALLIATIVE CARE/; 7098 results.
8. CINAHL; exp \*TERMINALLY ILL PATIENTS/; 3102 results.
9. CINAHL; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 8; 31115 results.
10. CINAHL; (death OR dying OR die).ti,ab; 34693 results.
11. CINAHL; 9 AND 10; 3447 results.
12. CINAHL; preference\$.ti,ab; 3830 results.
13. CINAHL; choice\$.ti,ab; 14712 results.
14. CINAHL; 12 OR 13; 18092 results.
15. CINAHL; 11 AND 14; 126 results.

### CINAHL search 2

1. CINAHL; \*ADVANCE CARE PLANNING/; 100 results.
2. CINAHL; exp \*ADVANCE DIRECTIVES/; 2583 results.
3. CINAHL; exp \*HOME HEALTH CARE/; 16830 results.
4. CINAHL; \*HOSPICES/ OR \*HOSPICE PATIENTS/ OR \*HOSPICE CARE/; 3628 results.
5. CINAHL; \*LIVING WILLS/; 259 results.
6. CINAHL; \*PALLIATIVE CARE/; 7098 results.
7. CINAHL; \*PALLIATIVE CARE/; 7098 results.
8. CINAHL; exp \*TERMINALLY ILL PATIENTS/; 3102 results.
9. CINAHL; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 8; 31115 results.
10. CINAHL; (death OR dying OR die).ti,ab; 34693 results.
11. CINAHL; 9 AND 10; 3447 results.
12. CINAHL; preference\$.ti,ab; 3830 results.
13. CINAHL; choice\$.ti,ab; 14712 results.
14. CINAHL; 12 OR 13; 18092 results.
15. CINAHL; 11 AND 14; 126 results.
16. CINAHL; \*OPEN-ENDED QUESTIONNAIRES/ OR \*STRUCTURED QUESTIONNAIRES/ OR \*END-OF-LIFE COMFORT QUESTIONNAIRES/ OR exp \*QUESTIONNAIRES/; 2904 results.
17. CINAHL; exp \*RESEARCH INSTRUMENTS/; 24071 results.
18. CINAHL; exp \*FOCUS GROUPS/; 332 results.
19. CINAHL; 16 OR 17 OR 18; 24396 results.
20. CINAHL; 11 AND 19; 33 results.

### CINAHL search 3

1. CINAHL; \*ADVANCE CARE PLANNING/; 100 results.

2. CINAHL; exp \*ADVANCE DIRECTIVES/; 2583 results.
3. CINAHL; exp \*HOME HEALTH CARE/; 16830 results.
4. CINAHL; \*HOSPICES/ OR \*HOSPICE PATIENTS/ OR \*HOSPICE CARE/; 3628 results.
5. CINAHL; \*LIVING WILLS/; 259 results.
6. CINAHL; \*PALLIATIVE CARE/; 7098 results.
7. CINAHL; \*PALLIATIVE CARE/; 7098 results.
8. CINAHL; exp \*TERMINALLY ILL PATIENTS/; 3102 results.
9. CINAHL; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 8; 31115 results.
10. CINAHL; (death OR dying OR die).ti,ab; 34693 results.
11. CINAHL; 9 AND 10; 3447 results.
12. CINAHL; preference\$.ti,ab; 3830 results.
13. CINAHL; choice\$.ti,ab; 14712 results.
14. CINAHL; 12 OR 13; 18092 results.
15. CINAHL; 11 AND 14; 126 results.
16. CINAHL; \*OPEN-ENDED QUESTIONNAIRES/ OR \*STRUCTURED QUESTIONNAIRES/ OR \*END-OF-LIFE COMFORT QUESTIONNAIRES/ OR exp \*QUESTIONNAIRES/; 2904 results.
17. CINAHL; exp \*RESEARCH INSTRUMENTS/; 24071 results.
18. CINAHL; exp \*FOCUS GROUPS/; 332 results.
19. CINAHL; 16 OR 17 OR 18; 24396 results.
20. CINAHL; 11 AND 19; 33 results.
21. CINAHL; 11 [Limit to: (Publication Type Questionnaire/Scale)]; 60 results.

#### MEDLINE search 1

1. MEDLINE; exp \*PATIENT SATISFACTION/; 13359 results.
2. MEDLINE; (death OR die OR dying).ti,ab; 348135 results.
3. MEDLINE; 1 AND 2; 196 results.
4. MEDLINE; questionnaire.ti,ab; 151657 results.
5. MEDLINE; exp QUESTIONNAIRES/; 191354 results.
6. MEDLINE; 4 OR 5; 270539 results.
7. MEDLINE; 3 AND 6; 57 results.

#### MEDLINE search2

1. MEDLINE; exp \*PATIENT SATISFACTION/; 13359 results.
2. MEDLINE; (death OR die OR dying).ti,ab; 348135 results.
3. MEDLINE; 1 AND 2; 196 results.
4. MEDLINE; questionnaire.ti,ab; 151657 results.
5. MEDLINE; exp QUESTIONNAIRES/; 191354 results.
6. MEDLINE; 4 OR 5; 270539 results.
7. MEDLINE; 3 AND 6; 57 results.
8. MEDLINE; exp \*ADVANCE CARE PLANNING/; 3200 results.
9. MEDLINE; exp \*ADVANCE DIRECTIVES/; 2935 results.
10. MEDLINE; exp \*TERMINAL CARE/ OR exp \*PALLIATIVE CARE/; 36935 results.
11. MEDLINE; exp \*ATTITUDE TO DEATH/ OR exp \*HOSPICE CARE/ OR exp \*HOSPICES/; 10979 results.
12. MEDLINE; exp \*TERMINALLY ILL/; 2078 results.



13. MEDLINE; exp \*DEATH/; 41664 results.
14. MEDLINE; 8 OR 9 OR 10 OR 11 OR 12 OR 13; 86601 results.
15. MEDLINE; 1 AND 14; 291 results.

#### EMBASE search 1

1. EMBASE; exp PATIENT DECISION MAKING/; 1231 results.
2. EMBASE; (death OR dying).ti,ab; 259006 results.
3. EMBASE; 1 AND 2; 59 results.

#### EMBASE search 2

1. EMBASE; exp PATIENT DECISION MAKING/; 1231 results.
2. EMBASE; (death OR dying).ti,ab; 259006 results.
3. EMBASE; 1 AND 2; 59 results.
4. EMBASE; exp LIVING WILL/; 1386 results.
5. EMBASE; exp TERMINAL CARE/ OR exp DYING/ OR exp TERMINAL DISEASE/; 14996 results.
6. EMBASE; exp HOSPICE/ OR exp HOSPICE CARE/; 2349 results.
7. EMBASE; exp PALLIATIVE THERAPY/; 23724 results.
8. EMBASE; exp HOME CARE/; 16188 results.
9. EMBASE; exp CANCER MORTALITY/ OR exp CANCER PATIENT/ OR exp DYING/; 67132 results.
10. EMBASE; 4 AND 5 AND 6 AND 7 AND 8 AND 9; 2 results.
11. EMBASE; 4 OR 5 OR 6 OR 7 OR 8 OR 9; 111015 results.
12. EMBASE; 1 AND 11; 222 results.
13. EMBASE; (approach OR discussion OR instrument OR proforma OR questionnaire OR tool OR toolkit OR preferences).ti,ab; 708626 results.
14. EMBASE; 12 AND 13; 63 results.

## Appendix 2 – Interview Schedules

### STAFF

1. I would first like to ask if you are you familiar with the Preference Questionnaire that is in the Patient Profile? (*hold up sample*)
  - a. Do you usually complete all 13 questions?
  - b. When do you usually complete it? (During your first encounter or first assessment with the patient? During follow up assessments?)
  - c. How do you usually complete it? Do you go through it question by question with the patient, do you complete it afterwards; what is your usual process?
  - d. Do you think it is useful?/How important do you think it is to complete it?
    - i. Which parts are the most useful or helpful, and which are the least useful?
2. How often do you complete question 10 on the Preference Questionnaire which is 'Does the patient have a preferred place of care when they are dying?'
  - a. What is difficult about asking this question?
  - b. Is there anything that could be done to help you to ask every patient?
  - c. Does a 'place of care' and a 'place of death' mean the same thing to you? Do they mean the same as a 'place of care when you are dying?'
3. How comfortable do you feel discussing dying with patients and their families or relatives?
  - a. What kind of language do you use when discussing death and dying?
    - i. Do you use other, gentler words or euphemisms with patients instead of saying 'death' and 'dying'?
4. How do you decide if a conversation about future plans and wishes is appropriate for a patient?
  - a. When do you think this discussion should be had with patients?
  - b. How do you feel about helping patients to decide where they want to be cared for and what type of care they would want in their final days?
5. Is there anything that could be done so that you would feel more comfortable and confident in asking patients where they would like to spend their final days? (better structure in the questionnaire, more training, increasing patient awareness of your expectations of them?)
  - a. What could be done to help you be more direct with patients?

### PATIENTS

1. Tell me a bit about your situation, how long you've been [using hospice services], and whether you have someone who cares for you at home.
2. If someone asks you 'where do you want to be cared for?', would you assume that they are asking you where you want to be when you are dying?
  - a. Have you made a decision about where you want to be when you are dying?
  - b. How did you make this decision?
  - c. Who have you discussed it with?
3. Have you been asked by a nurse or doctor from the hospice about where you would like to be cared for when you are dying?

- a. YES
    - i. How did they do it?
    - ii. Did it seem appropriate at the time?
    - iii. What could have been better about the way they asked?
  - b. NO
    - i. If you haven't been asked, would you want to be?
    - ii. Who do you think is the right person to have this conversation with?
    - iii. When would be the best time to ask?
4. Is it important to you to have your wishes for future care written down by nurses and doctors?
    - a. Why do you feel it is or isn't important?
    - b. Would you want to have a copy of what they have written down?
  5. What is the best way for a nurse or doctor to ask you about your wishes for your future care?
    - a. Who is the best person to ask you?
    - b. When is the best time to ask?
    - c. How would you suggest a nurse or doctor approach a patient who doesn't feel ready to talk about their choices for future care?

#### CARERS

1. Briefly, your relationship with the hospice, what sort of input have you or your relative have had from them, whether they attend the day hospice, or if you've just had one visit and whether you've been involved in making decisions about the type of care your relative receives.
2. I'd like to first define some words and phrases that we use when talking about 'end of life care', and I want to know what they mean to you. Specifically whether there's a difference between a 'place of care' and a 'place of death'. So for example, if a nurse from the hospice asks you, 'where would you like your relative to be cared for?' does that also imply that they are asking about where you would like your relative to be when they are nearing the end of their life? Or does it exclude the dying process?
  - a. Is 'place of care' a gentler word for 'place of death'? Does a 'place where you are dying' mean the same things as a 'place of death'?
3. Have you been asked by someone at the hospice about where you would like your relative to be cared for?
  - a. How did they do it?
  - b. Did it seem appropriate at the time?
  - c. What could have been better about the way they asked?
  - d. If you haven't been asked, would you want to be?
4. Have you been asked by someone at the hospice about where you would like your relative to be cared for in the future when they are dying?
  - a. How did they do it?
  - b. Did it seem appropriate at the time?
  - c. What could have been better about the way they asked?
  - d. If you haven't been asked, would you want to be?
  - e. Who do you think is the right person to have this conversation with?
5. Is it important to you to have your wishes for the future care of your relative to be written down by nurses and doctors?

- a. Why do you feel it is or isn't important?
- 6. What is the best way for a nurse or doctor to ask you about your wishes for your relative's future care?
  - a. Who is the best person to ask you?
  - b. When is the best time to ask?
  - c. How would you suggest a nurse or doctor approach a patient who doesn't feel ready to talk about their choices for future care?

#### BEREAVED CARERS

1. I'd like to start by asking if you were involved in making decisions about where your relative was cared for by the hospice?
  - a. Was the place that they were cared for important to you?
  - b. Were you given a chance to express your wishes for where they should be cared for?
2. Were you given a chance to express your wishes for where your relative could die?
  - a. Who asked for your choice?
  - b. How did they ask you?
  - c. Did it seem appropriate when they asked? (the timing of it, how it was said)
  - d. Was your relative asked where they wanted to be?
  - e. [If no] Would you have liked to have had a choice?
  - f. How would you have felt if your visiting nurse (or CNS) had given you a form asking about your wishes for care that you would then fill in in the time between their visits?
  - g. Were you prepared to answer questions about where you would like your relative to die when they asked you?
    - i. What (or who) prepared you?
  - h. Did you see the nurse write down your wishes? Was it important to you to know that your wishes were written down somewhere? Do you think it made a difference to your relative's care?
3. How did you feel about discussing dying with nurses and doctors at the hospice?
  - a. Were they direct with you, did you understand them easily, or were there sometimes misunderstandings?
  - b. When would have been the best time for them to discuss making plans for your relative's care in their final days?
4. Does a 'place of care' and a 'place of death' mean the same thing or different things to you?

## Appendix 3 – Patient Preference Questionnaire

### Patient Preference Questionnaire

Patient name: \_\_\_\_\_

Patient ID: \_\_\_\_\_

Hospice No.: \_\_\_\_\_

Date: \_\_\_\_\_

These decisions must always be reconfirmed with the patient whilst they retain capacity. If lacking capacity a formally constructed advance directive or properly appointed proxy will take precedence.

1. What is the patient's understanding of their diagnosis and prognosis?
  
  
  
  
  
  
  
  
  
  
2. What is the patient's preferences for the amount of information they wish to receive?  
 Not to know  
 Limited information  
 To know all the details
  
  
  
  
  
  
  
  
  
  
3. Does the patient feel the information they have received so far has been:  
 Too little                       About right                       Too much
  
  
  
  
  
  
  
  
  
  
4. Does the patient give permission for us to discuss their condition with their family (including young children) and close friends?  
 Yes                       No
  
  
  
  
  
  
  
  
  
  
5. Are there identified people we should not disclose information to?

6. Are there people the patient would want to be present for important decisions?
  
  
  
  
  
  
  
  
  
  
7. Is there an advanced statement and/or a legally appointed lasting power of attorney (someone who can make health care decisions if the patient is unable)? Please enter the relevant codes on the patient information system.
  
  
  
  
  
  
  
  
  
  
8. Does the patient have preferences for or against future treatments?
  
  
  
  
  
  
  
  
  
  
9. Has the patient identified individuals that should be consulted regarding health care decisions should they lose capacity?
  
  
  
  
  
  
  
  
  
  
10. Current CPR status. Please indicate the date, reason for decision, discussion and review date.
  
  
  
  
  
  
  
  
  
  
11. Does the patient carry a donor card? Do they have any preferences regarding organ donations?
  
  
  
  
  
  
  
  
  
  
12. Does the patient wish to receive copies of correspondences from the Hospice?

**Preferred place of care when dying**

This section is for recording and tracking preferences for where patients would like to be when they are dying. The following are basic guidelines which should be used (for a full explanation on how to complete and use this form please refer to the *Preferred Place of Care When Dying Toolkit*):

- The form should be revised with the patient whenever there is a change in their condition.
- You may write notes for a ticked box in the blank space to the right of each entry.
- Indicate preferences for both the patient (P) and carer (C), if known.
- Tick only 1 box each for patient and carer. If they have a preference of 2 or more settings (e.g. either hospice or home), then tick 'other' and write this in. If they say 'home, unless...', then tick home and write a note in the space to the right.
- An entry should be made for each meeting/visit until a preference is made, and then only after if the preference changes. No new entry is needed if the preference is only reconfirmed. To indicate reconfirmation, write 'reconfirmed' and the date next to the entry that specifies the preference.

**ENTRY 1— First Assessment**

Date: .....

Staff initials: .....

P C

- Opportunity to discuss did not arise:* .....
- Home (where P is currently living)
- Care Home (if not already living in a care home)
- Hospital
- Hospice
- No preference
- Does not wish to discuss at this time
- Other: .....

Patient's condition: .....

.....

**ENTRY 2**

Date: .....

Staff initials: .....

P C

- Opportunity to discuss did not arise:* .....
- Home (where P is currently living)
- Care Home (if not already living in a care home)
- Hospital
- Hospice
- No preference
- Does not wish to discuss at this time
- Other: .....

Patient's condition / reason for asking: .....

.....

**ENTRY 3**

Date:.....

Staff initials:.....

P C

- Opportunity to discuss did not arise:*.....
- Home (where they are currently living)
- Care Home (if not already living in a care home)
- Hospital
- Hospice
- No preference
- Does not wish to discuss at this time
- Other:.....

Patient's condition / reason for asking:.....  
.....

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**ENTRY 4**

Date:.....

Staff initials:.....

P C

- Opportunity to discuss did not arise:*.....
- Home (where they are currently living)
- Care Home (if not already living in a care home)
- Hospital
- Hospice
- No preference
- Does not wish to discuss at this time
- Other:.....

Patient's condition / reason for asking:.....  
  .....

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**ENTRY 5**

Date:.....

Staff initials:.....

P C

- Opportunity to discuss did not arise:*.....
- Home (where they are currently living)
- Care Home (if not already living in a care home)
- Hospital
- Hospice
- No preference
- Does not wish to discuss at this time
- Other:.....

Patient's condition / reason for asking:.....  
.....

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