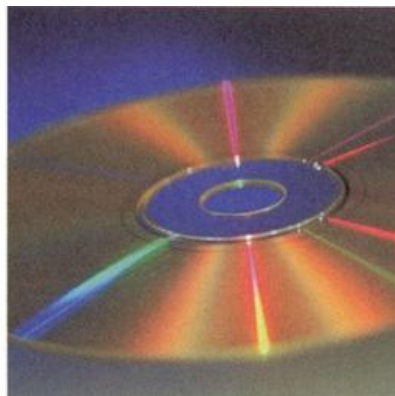
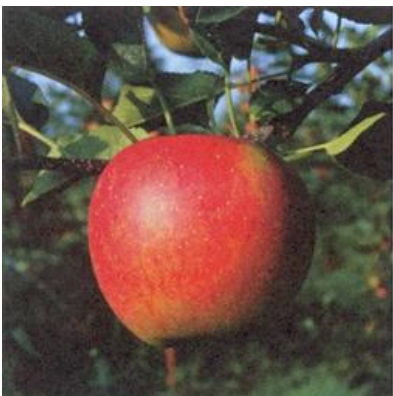


Developing a Patient Preference Questionnaire for Place of Care When Dying

Phase 2: Nursing home, primary care and
secondary care settings



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October 2010

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Commissioned by:
Sheila Pitt, Head of Cancer, Long Term
Conditions and Therapies
Eastern and Coastal Kent PCT

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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*. 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 there is little evidence in the literature on best practice for recording patient preferences on place of care and death. A good questionnaire for collecting preferences and specialised staff training should ensure that preferences are collected routinely and accurately.

Aims and Objectives

2. The aim of this study was to use exploratory methods to develop a toolkit consisting of a questionnaire and training guide for three healthcare settings which would be acceptable to patients, carers or family members and healthcare professionals for recording preferences for place of care and death with end of life patients.

Methods

3. This study follows on from work that was done in Phase 1 of the study which developed recommendations for eliciting preferences in a hospice setting. The three settings which were addressed in this phase were a nursing home, GP surgery (primary care), and hospital (secondary care). A literature review was conducted during the first phase of the study and the findings are presented here. Interviews and focus groups were conducted with healthcare professionals, residents and carers.

Literature review

4. 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.
5. The five themes that were identified as useful for developing a questionnaire were: involving others in care decisions, determining patients' informational needs, ordering questions in a progression, acceptable wording and space for recording notes.
6. Four themes that were to be incorporated in a training element include: timing of end of life discussions, consistent professional judgement, giving patients information prior to the discussion, and developing a trusting relationship between patient and healthcare professional.

Nursing home

7. Five nursing home staff, three residents, and seven family members took part in separate focus groups. The nursing home currently includes an advance care plan as a part of the resident's care profile.
8. Nursing home staff took a pragmatic approach to asking about end of life preferences which was readily accepted by residents. Asking about preferences was part of the 'paperwork' and as death was viewed as an inevitable outcome of being resident in a care home, it did not seem unreasonable to residents or families to have to discuss it.

9. Residents, and to some degree families, struggled to remember when preferences had been expressed to nursing home staff, which was sometimes troubling to residents and families. Not remembering having made a preference may not be problematic as long as this preference does not change, though staff will need to be able to recognise when choices may change, such as with a change in health status.
10. There was confusion among both residents and families over whether residents could stay in the nursing home to the end of their lives with some believing that they would have to leave the home if they became too poorly. Families and residents need clarity when it comes to the options that are available to them at the end of life.
11. Family members of those unable to communicate their wishes found it particularly stressful when they could not remember if their relative had previously expressed a preference for their care at the end of life. Wishes should be discussed as early as possible so as to reduce the impact of deteriorating memory. Families also did not want to be responsible for having to give bad news to their relative especially if they suffered from cognitive impairment.
12. From the focus groups and a review of the assessment material currently used by the nursing home, it was decided that it was not necessary to create a questionnaire specific for the nursing home as the current documentation was comprehensive and well used by staff and residents. Therefore the piloting period was not utilised. The documentation could potentially be used as a model or template for other care homes, though perhaps with some modifications.

Primary care

13. One researcher conducted interviews individually with two GPs from one surgery in East Kent. The key contact who identified participant GPs in the surgery was not able to identify any patients or carers who were not already under hospice care (exclusion criteria as this was covered in the first phase) for participation.
14. The two GPs saw themselves as central to a patient's care, from diagnosis to end of life. They are a constant point of contact and resource in the patient's changing care needs. The GPs saw themselves as responsible for referring and managing patient care.
15. Having longstanding relationships with their patients was important to the GPs for helping patients to make decisions and express their wishes. The nature of the relationship between GPs and patients in identifying illness and exploring treatments meant that the dialogue of preferences and choices was constantly evolving and the GPs were aware that patients' wishes changed over time as their illness progressed.
16. Both GPs cited their experience of working with palliative care patients and interest in palliative care as important for making them more comfortable with discussing end of life choices. They recognised that palliative care training is not widespread across primary care, even though end of life discussions are seen as 'bread and butter' of primary care. Standardised training for GPs in how to deal with palliative care patients and how to handle their own emotions resulting from such discussions would be beneficial for both patients and healthcare professionals.
17. The GPs both stated that they felt that hospitals did not communicate effectively with patients about the status and treatability of their condition. This resulted in patient confusion which made discussing preferences for death difficult. Having accurate records of what has been discussed in the hospital or with other care providers with both factual and narrative information may help GPs to manage patient care and expectations. Such information could be conveyed in a standardised letter from hospital to the GP.
18. Assessment forms and care plans were kept electronically within the surgery, including questions pertaining to end of life care and wishes. However, the electronic form only

contained three coded options for preferred place of death: home, hospice and hospital. The form could be improved to include nursing home, friend/relative's home, and distinguish between acute and cottage hospitals. The piloting phase was not utilised as it was not feasible to integrate a paper based form into the electronic system and it was not possible to alter the electronic system.

Secondary care

19. Interviews with a physiotherapist and ward nurse and one group interview with two registrars were conducted in a hospital in East Kent. Participants cared for a wide range of patients on different wards, from older people to emergency care, but generally did not have longstanding relationships with patients.
20. Though the doctors were identified as primarily responsible for discussing end of life preferences, this recognised responsibility did not mean that doctors were any more comfortable with the discussion than those who did not see it as their responsibility.
21. The nurse and physiotherapist did not feel they were in a position to discuss end of life preferences as they were not always certain of what the patient had already been told by the doctor and what they understood. They seemed to be concerned about upsetting patients by talking to them about something they had not yet been told. Better communication both verbally and written between medical and nursing staff is needed so that all members of care team are aware of what the patient has been told whilst in hospital. Training in communicating with end of life patients could also be utilised to ensure that hospital staff are comfortable discussing choices with patients.
22. The focus in hospitals is generally on treatment and improvement. Staff stated that they must respond clinically if patients present in the emergency care centre even if they have a terminal illness. This has implications for patients who have chosen to die at home as they may have to remain in hospital to be treated when they might prefer to go home.
23. A stepped approach to conveying information in hospital might be particularly useful as patients may have little knowledge about their condition prior to the hospital episode. This may also be useful as it was reported by participants that they were often unsure of whether the patient understood what they were told. Having room to record patient's reactions and feelings in the care notes may be very useful for when patients are referred to other healthcare professionals.
24. The hospital did not use a standard form for recording patients' end of life wishes. Any such discussions and decisions were recorded in the patient's notes. For those patients assessed as having palliative care needs there should perhaps be a standard form or section of the care plan which could be used to inform other care providers of relevant information, such as the patient's understanding of their diagnosis and prognosis, expectations of treatment, what has been discussed with the family or carer, and whether wishes for end of life care have been discussed.

Comparisons between the three care settings

25. In all three settings there was consensus that doctors are responsible for diagnosis and prognosis discussions, even though it was acknowledged that all healthcare professionals should be responsible for end of life care discussions. Once these initial difficult issues were discussed, other care providers were able to discuss care planning options as they related to their area of expertise.
26. The emotional experience of giving bad news and having end of life discussions was described as a challenging professional task. This was particularly so where news was

unexpected or if the patient was relatively young. More training in dealing with emotions and better documentation of wishes could potentially alleviate some of this strain.

27. Record keeping of patient preferences was better developed where patient caseloads were more constant, i.e. the nursing home had very clear, consistent and complete records, whereas records in the hospital had more variable content.
28. In relation to the importance of the patient-healthcare professional relationship, those with more frequent access and longer relationships with patients may have greater ability to have end of life discussions. Where these types of relationships do not exist, if the information is clearly relevant to the patient's situation then this may be a substitute particularly if the information is delivered by a healthcare professional with a clear role in end of life care.

Recommendations

29. Palliative care patients need to be given clear information about the options available to them for end of life care. There should be a clear pathway of care for patients with all conditions so that confusion is minimised during crises and when the patient is nearing the end of their life.
30. Documentation for recording preferences should be improved to contain a wide variety of possible places of death for the patient, which may include: home, hospice, acute and cottage hospital, relative/friend's home, and nursing home. If patients are really to be given a choice or chance to express a preference, then they must be aware of all possible options.
31. Good documentation which includes commentary provided by the healthcare professional and patient could then be easily transferred between healthcare professionals in different settings to improve communication. It is important that healthcare professionals have an understanding of what others have discussed with the patient so that they know where to pick up the discussion or what approach to take with patients. As preferences are not often discussed, any means by which healthcare professionals can be made to feel more comfortable in initiating the discussion should be utilised.
32. Training in successful ways to conduct end of life discussions and in how to deal with the emotional burden that these discussions may pose for healthcare professionals from all care settings is necessary and should be ongoing.

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 discussing 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 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 can meet these preferences. A good questionnaire for collecting preferences and specialised staff training should ensure that preferences are collected routinely and accurately.

This study received ethical approval from the East Kent Research Ethics Committee.

2 Aims and Objectives

The aim of this study was to use exploratory methods to develop a toolkit consisting of a questionnaire and training guide for three healthcare settings which would be acceptable to patients, carers or family members and healthcare professionals for recording preferences for place of care and death with end of life patients. The objectives were to:

1. Create a questionnaire for collecting preferences on place of care and death.
2. Identify issues of collecting preferences from both the perspective of service users and healthcare professionals to create a training element.

3 Methodology

This study follows on from work that was done in Phase 1 of the study which developed recommendations for eliciting preferences in a hospice setting. The three settings which were addressed in this phase were a nursing home, GP surgery (primary care), and hospital (secondary care). A literature review was conducted during the first phase which is relevant to Phase 2 and the

findings will be presented in the following section. The findings from each setting are presented in order of completion: nursing home, primary care and secondary care.

3.1 Sample and Participants

In our experience from Phase 1 with hospices, focus groups worked best with no more than four patients or carers and therefore we aimed to have groups of this size in this phase. As the number of participants per group was small, we aimed to have two focus groups each with patients and carers in each setting in order to obtain a range of views. One to one interviews were conducted if it was not possible to arrange focus groups.

3.2 Inclusion/Exclusion criteria

Patients/ Residents

Patients or residents were included from each setting if they met the following criteria:

- Nursing home
 - They were currently resident in a nursing home.
- Primary care
 - They had a life-limiting condition defined as less than 12 months to live;
 - Their primary point of contact for end of life care was their GP (no hospice involvement).
- Secondary care
 - They had a life-limiting condition defined as less than 12 months to live;
 - They were in receipt of end of life care from secondary care.

Carers

Carers were included if they identified themselves as a carer to someone with a life-limiting condition. In the case of the nursing home group, carers were also included if they were actively involved in making care decisions for someone with a life-limiting condition but did not necessarily provide hands-on care as this was provided by the nursing home.

Healthcare Professionals

Healthcare professionals were included in each group if they were responsible for creating care plans and identifying patient preferences for care.

In all three groups, participants were excluded if they were unable to give consent. Participants also had to be mobile enough to attend the focus group or interview.

3.3 Focus groups and interviews

Focus group discussions and interviews were audio recorded and lasted from 21 to 53 minutes. The interview schedule was semi-structured which allowed for further exploration of issues that participants introduced. The interviews covered the following topics:

- How preferences for end of life care and death are recorded;
- acceptability of discussing death with family;
- acceptability of discussing death with healthcare professionals;
- interpretation of 'place of care' versus 'place of dying';
- appropriateness of asking preferences;
- how decisions about place of care and dying are made; and
- importance of having ownership over the care plan.

The focus groups were led by two researchers where possible; one led the discussion while the other took additional notes and also contributed to the discussion as needed as topics unfolded. One to one interviews were conducted if there were insufficient numbers for a focus group. The researchers had to be flexible in their methods in order to take advantage of the time that participants had available, particularly with healthcare professionals. The focus group discussions and interviews were transcribed and then analysed thematically (Liamputtong and Ezzy, 2005). Participants received a voucher to a local shop to thank them for their time after the interview.

3.4 Questionnaire development and piloting

After the focus groups and interviews we had planned to create a setting-specific questionnaire based on the one developed during the hospice phase and then ask healthcare professionals to pilot it with patients or residents. However, this stage was not utilised for the following reasons.

In the nursing home setting, the care home manager supplied the researchers with a copy of their current form for recording resident's end of life wishes. Upon scrutinizing the form and from the feedback from the focus groups it was deemed that the form was fit for purpose and no further alterations would be necessary. A copy of this form is included in the appendix [appendix 1].

In the primary care setting, an electronic system of recording preferences was already in place and therefore piloting a paper based version was not feasible. A copy of this electronic form is included in the appendix [appendix 2] and recommendations for possible alterations to the form are included in the section on primary care.

The secondary care setting was the last setting to be explored and due to time constraints we were unable to thoroughly develop and pilot a questionnaire. We do however propose possible ways to structure a questionnaire and also include recommendations for possible steps forward in the section on secondary care.

Part of this research was to create a training element to accompany the use of the questionnaires. However, because the questionnaires were not developed for reasons previously mentioned, we did not progress our findings for training from the literature review into a practical training element, but instead discuss opportunities for general training as they relate to our findings.

4 Literature Review Findings

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 a 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 in part, 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 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 a 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. Five themes were identified from the literature as useful in guiding the development of a 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 an 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).

4.2 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).

4.3 Assessment of the literature

Apparent in the literature was a need for training for healthcare professionals 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 better 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.

There is little practical guidance in the literature on developing a questionnaire for identifying patient preferences at the end of life. 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 direct feedback from end of life patients (Barnes *et al*, 2007; 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.

5 Nursing Home

5.1 Participants

One nursing home in East Kent was used for this study. The home provides both nursing and residential care and can accommodate up to 47 residents.

Participants for the focus groups were recruited by the nursing home manager. Staff and residents were approached personally by the manager and given an information sheet. Five nursing home staff took part in the focus group which was facilitated by two researchers. The participants were a mix of staff who provide care including care staff, nurses and management. Six residents were approached to take part in the focus group of which three did. Ten family members were sent written invitations of which five took part in one focus group and two in a second focus group.

It is worth noting that all seven family members who participated had relatives in the home who either suffered from dementia or had communication difficulties due to stroke or other illness. Therefore the family members were primarily responsible for making choices on behalf of their relative.

5.2 Findings from the focus groups

Nursing Home Staff

How do you initiate the discussion on end of life choices with residents and their families?

Questions on end of life choices are included as part of the in-depth nursing home assessment that was completed when the resident moves into the home [appendix 1]. A copy of the advance care plan which includes the resident's wishes was kept in the resident's room. Therefore staff generally said it was easy to bring up the discussion by stating that it was a part of the routine assessment and that it was beneficial to the resident to complete it as soon as possible after moving into the nursing home:

what I tend to do is when they first come into the home and say 'look, we need this information. We might as well get it over and done with, then we've got it all.'

if you're light-hearted about it and say, 'look, we'll get all this stuff out of the way now and then we can get on to the nice stuff', or 'sorry about this, but we have to talk about what you want when you die- we're all going to go sometime.'

Though this type of approach may have been effective in initiating the discussion, it may also have trivialised the discussion as it was treated more as a box ticking exercise that may or may not have been appropriate to the resident's health status.

Staff often gave residents advance notice that they wanted to discuss their preferences and made an appointment to speak with them a couple of weeks after moving into the nursing home. Our findings from phase 1 in hospices suggested that advance notice may improve the likelihood that people will discuss their preferences (Holdsworth and King, 2009). Alternatively, they gave the resident the form to complete themselves and then discussed it at their next meeting. The way that staff chose to

complete the form depended on the resident's capacity and whether they felt it was appropriate for the resident, either to complete it jointly or on their own. The timing for completing the assessment also depended on the residents' diagnosis, whether they had months or years to live.

How do you inform residents that they might be dying?

In most cases residents will have been told by their GP or consultant that they have a life-limiting illness, though it was usually the responsibility of the nursing home to create the advance care plan with the resident. Staff also said that residents sometimes know when they are coming to the end of their lives and will bring it up with staff.

Staff said that most residents had not created an advance directive before moving into the nursing home. One nurse stated that she would prefer if residents came into the home with an advance directive. This would be especially preferable in cases where the new resident has dementia and it is not possible to ascertain their preferences. As dementia is highly prevalent in nursing homes, it is often left to family members to make choices on behalf of the resident.

Staff acknowledged that there is sometimes a tension between what they believe is the best course of action for the resident and what family members want, especially with regards to resuscitation. In most cases staff expressed the opinion that residents with life-limiting conditions should not be resuscitated, though sometimes family members wanted their relative resuscitated or admitted to hospital or the resident may have expressed a preference for resuscitation even if they were quite elderly and frail. Staff felt that this was often not in the best interest of the resident. However, one of the nurses explained a time when she was in the position of a family member and explains that she had a personal view that differed from her professional view of how things should be handled:

I wouldn't have been able to sit there and just say 'let her go'. I would have wanted them to try and resuscitate her and do stuff because she'd just had major surgery, even though she couldn't have recovered, that side of me (nursing) would've forgotten about that and I'd try and get my mum back.

This quote highlights the emotionally difficult situation that families find themselves in when having to make decisions on behalf of their loved ones and that decisions that are taken can be clouded emotionally and may not be in the best interest of the resident.

Residents and family members

Have you been asked your preferences?

Two of the three residents said they did not recall discussing their end of life preferences with nursing home staff. However, after the focus group the nursing home manager said that they both suffered from short term memory loss and that they both previously discussed end of life wishes with staff. Though they did not remember, they said they were happy to discuss their preferences and one expressed concern that her preferences may not be written down as she did not recall discussing them. However she was fairly certain that her family knew what she wanted at the end of life in any case.

The majority of family members recalled that they had discussed preferences on behalf of their family member who had cognitive impairment with nursing home staff.

Who should ask your preference?

There were differing opinions on which staff member should be responsible for asking about preferences. Some participants, especially residents, felt that it should be the resident's personal

carer or key worker as they are likely to know the resident best. One relative felt that the matron or person who oversees the key workers should be responsible for asking and helping to make decisions about preferences:

I think it needs to be the person above the key worker who actually talks about that part of the responsibility of the key worker or all the rest of the people are going to have to read the notes, aren't they. Yes, I think I would be happier because I assume that the matron or whoever it is will be overseeing all of the cases, which leaves the key worker apart from that decision and she takes her orders from the matron who's discussed it with the carer.

This relative may have felt that if preferences were discussed and recorded by someone seen as having authority in the nursing home then they are more likely to be followed.

When should you be asked your preference?

Generally family members felt that discussing issues related to death during the initial meetings with the nursing home staff were appropriate.

I think if people raise it with you and it's from the word go then there's clarity isn't there?

Residents and families found it less startling to be asked about end of life choices when they were asked as part of a series of questions related to end of life, such as whether a will had been made. This reflects findings in the literature (Barnes *et al*, 2007; Borreani *et al*, 2008) about the importance of how the topic is introduced.

There were occasions when asking at first admission was not deemed appropriate however, such as when a person was admitted to the home in a hurry or when it was not clear to the relatives why they were being admitted to the nursing home.

I mean we'd had high stress with everything really so coming here was a tremendous relief but you're still ... I mean speaking as I feel now, I was not in a good condition to be discussing that [dying] so quickly, especially as I was so disappointed because I thought he was coming home to get better.

This supports previous findings in the literature (Barnes *et al*, 2007) that preferences should not be asked during stressful life events.

Do place of care and place of dying mean the same thing to you?

Residents felt that they had entered the nursing home for the rest of their life and so perceptions about place of care and place of death were the same. Entering a care home was viewed of as having made a decision about where the final stages of life would be lived and therefore questions about place of care were inferred to relate to the end of life, particularly for one resident:

I think the inference is where do you want to be when you're in your last stages of life?- that would be my inference from that question.

This assumption was also true for one relative:

I mean I think we all accept don't we that when our nearest and dearest have to live in a home, that's one step nearer, you know to the end of their lives because you wouldn't be doing it otherwise would you.

However, for most other relatives they felt the question would need to be more direct for them to understand that they were being asked about dying.

5.3 Assessment of the existing questionnaire

As stated previously, a copy of the resident's advance care plan [appendix 1] is a part of the resident's profile and is kept in the resident's room signifying their ownership over their own care plan. However, two of the three residents in the focus group were not aware that the care plan was kept there. For many care home residents who have memory problems ownership of the care plan may be more symbolic to the care staff than practical to the resident.

The advance care plan covers basic issues related to end of life, but refers to 'preferred place of care' without specifying that this pertains to the dying phase. However, from what the residents said they assumed that this question related to end of life, though for relatives speaking on behalf of the resident this may be ambiguous. Residents are able to give a first and second choice, but there does not seem to be sufficient room to write additional notes, such as under what circumstances the second choice would be preferable. For example, many patients receiving care from the hospice state that they would like to remain at home as long as their symptoms are controlled, but if not would prefer to spend their final days in the hospice. Additional space on the form might give the resident the option of recording this sort of complex statement.

One participant said that the only thing missing from this form was issues pertaining to the existence of a will and that this should be included. Related documents such as a will can be listed elsewhere in the resident's profile. Question 4 alludes to information that would be included in a will and thus it might be possible to simply state 'see will' in response to that question.

From the focus groups and a review of the assessment material currently used by the nursing home, it was decided that it was not necessary to create a questionnaire specific for the nursing home as the current documentation was comprehensive and well used by staff and residents. Therefore the piloting period was not utilised. The documentation could potentially be used as a model or template for other care homes, though perhaps with the recommendations described above, as the relevant information is captured in a simple form and on a single page. A few recommendations for practice are discussed in section 5.5.

5.4 Discussion of the Nursing Home findings

Nursing home staff may have an advantage in discussing resident preferences over other health and social care professionals. They have close and frequent contact with residents. This means they are in a better position to become acquainted with residents which as seen in the literature, having a trusting and established relationship can improve one's ability to raise such discussions (Conroy *et al*, 2009; Huggins and Brooks, 2007; Munday *et al*, 2009). Also, regular frequent contact with residents mean that staff may have more opportunities to raise the discussion with those who may be more reluctant to discuss end of life choices. In addition, entering a nursing home is itself a marker of a entering the final stages of life which may be a natural icebreaker for both staff and residents to discuss end of life choices. Most of the nursing home staff had experienced working other care settings, such as hospitals, and they felt that end of life discussions were easier to have in the nursing home setting.

There were four themes that impact on discussing preferences that came out of the focus group sessions: pragmatic approaches to preferences, memory, family relationships, and assumptions and uncertainty.

Pragmatic approaches to preferences

Staff took a pragmatic approach to asking about end of life preferences which was readily accepted by residents. Asking about preferences was part of the 'paperwork' and as death was viewed as an inevitable outcome of being resident in a care home, it did not seem unreasonable to residents or families to have to discuss it. Taking a pragmatic, rather than emotional approach to discussing death is likely the easiest approach for staff to complete what is essentially viewed as a box ticking exercise. However, this method may not meet the emotional or spiritual needs of the resident, though perhaps at intake it is not appropriate to have a spiritual discussion of death if it is some years off.

Memory

Perhaps because of the pragmatic and routine approach that is taken by staff to discussing preferences, residents, and to some degree families, struggled to remember when preferences had been expressed to nursing home staff. For one of the residents who had memory problems and did not recall making a preference, the possibility that she did not have a preference recorded was worrying to her. Not remembering having made a preference may not be problematic as long as this preference does not change. But what if the person has changed their mind and staff do not ask for their preference again because they already have a preference recorded? Conversely, repeatedly asking someone for their preference for place of death in order to maintain accurate records can be burdensome and focuses attention on dying rather than living. However, wishes are only likely to change if the resident's physical or emotional status has changed and therefore a review of preferences should be included as part of the overall package of care. For those with memory issues, maintaining accurate records on wishes will depend on staff skills to recognise when choices may change, such as with a change in health status.

Memory was also important for families, but in the sense of trying to remember if their family member who lacks capacity expressed a preference for what they wanted. Not being able to remember if a wish had been expressed was stressful for families. When families could not recall their relatives' wishes, they made decisions based on what they believed their relative would have wanted, though there often existed an element of doubt in the decisions made.

Family relationships

Families are central for many decisions that are made about a resident's care, particularly if a resident suffers from cognitive impairment. For some of the families participating in the study, even in husband and wife situations, there had been no previous discussion between them about what their wishes were for the end of their life should they not be able to express a wish themselves. Not discussing wishes for the end of life seems to be a particular issue among older generations where discussing death is taboo. However, this causes stress for families who then must try to make decisions on behalf of their loved ones.

Families also did not want to be responsible for having to give bad news to their family member, especially if the family member has cognitive impairment as it was challenging for family members to explain something upsetting to someone who has little understanding.

The focus group discussions also raised the question of whether families are able to act objectively when confronted with emotional choices about the care of their family member. There may be an element of denial about the closeness of death which families do not want to accept. Therefore decisions that may be taken, while comforting to the family, may not be in the best interest of the resident.

Assumptions and uncertainty

Assumptions about preferences and options for care at the end of life were often made by both residents and families. One of the residents assumed that staff knew what her wishes were and that her family knew as well. However, from the point of view of the families they often did not know what their relative wanted to have happen at the end of their life. The resident may have believed they expressed a preference to their family at some point in their life, but perhaps this was dismissed by the family at the time as not being a serious wish or forgotten as the wish was expressed in passing. If preferences are not communicated in a structured way, then they may not be considered as serious or remembered by family members.

Assumptions were also made about what options for care would be available to residents at the end of life. One of the family members assumed that if their relative deteriorated too much they would have to be admitted to hospital or hospice. One of the residents hoped that she could die in the care home, but was not sure. It appeared that options at the end of life were not always communicated clearly to residents and carers.

5.5 Recommendations

Families and residents need clarity when it comes to the options that are available to them at the end of life. People have preconceptions of what care homes can provide, perhaps confusing the provision differences between residential and nursing homes. It should be made clear to residents and families during the initial discussion on end of life choices what sort of care will be made available and under what circumstances it may be necessary for the resident to leave the home to be cared for elsewhere.

When raising the discussion of end of life choices the reason why preferences need to be discussed should be made clear to the resident or their relative. This is particularly important if the resident is healthy to avoid causing them anxiety by leading them to think that they are dying when they are not. It should also be made clear that though the care home aims to have a complete advance care plan as early as possible in the resident's stay, this care plan can be changed at any time and should the resident's health change, staff will likely check whether choices that have been made are still correct.

Communicating effectively with residents who have memory problems continues to be challenging. Wishes should be discussed as early as possible so as to reduce the impact of deteriorating memory. Relatives or named decisions makers should also be included in end of life discussions so that residents with memory problems have a representative who can help recall decisions.

6 Primary Care

6.1 Participants

One researcher conducted interviews individually with two GPs from one surgery in East Kent. We attempted to arrange interviews with district nurses based within the surgery, but were informed that we would need to seek additional governance approval as the PCT approval which was obtained for the GP surgery did not cover the district nurses. Due to the late notification of this additional process we were not able to gain approval within the timescale of the project.

The key contact who identified participant GPs in the surgery was not able to identify any patients or carers who were not already under hospice care (exclusion criteria) for participation.

6.2 Findings from the interviews

Do you usually ask patients with life-limiting conditions where they want to be cared for when they are dying?

Both GPs said that they have end of life discussions with patients; one GP stated that such discussions were '*bread and butter of general practice*'. However, the first important step to the initiating the conversation is to convey to the patient that they are dying, which itself is a difficult barrier to overcome:

we tend to deal with the immediate problems first and then once they know ... the thing is the patient shouldn't be in denial about what is happening.

Both said that it was important to recognise that patients changed their minds as their disease progressed:

Patients change their mind. They do change minds so when they would have told you something in the consultation, saying the place that they'd prefer to die at home. When things start going in that direction, suddenly they want to go into hospital, knowing very well the hospital can't do anything more, so we don't know if it is the patient's wish or the carer's wish which plays a predominant role at that point.

Changes in patient wishes were recorded as part of the patient's history rather than erased and overwritten by new preferences:

You can't go back and change what you've written but you can always make a note saying now the patient prefers to die at home, or at the hospital.

One GP said that patients could be helped to make decisions by giving them information about what they can expect as their illness progresses so that they can make informed decisions:

Clarity right from the start to know their prognosis and how it can be ... and in fact, be aware of how bad the disease is going to be because some of the times patients don't know that - how painful it's going to be or how ... or what would be the really nasty things which is going to come. If they know what the signs and symptoms are going to be much more clearly, then maybe that will prepare them to know what they- 'Would I be able to cope with this particular problem? Would I need more help from nursing?'

What kind of language do you use when discussing death and dying?

The GPs said they tailored their language to suit the needs of the patient, repeating words that the patient has used for clarity. However, one GP said that if he had to initiate the discussion, he used straightforward words so that his meaning was clear:

I often will reflect back words that patients use so if they're saying, you know, 'I know when I pass away I want to be at home' then I'll use the word pass away - there's no ambiguity there because it's clear what they've said but if I'm initiating the conversation, I'll just talk about death and dying, I think.

How comfortable do you feel discussing dying with patients and their families or relatives?

Both GPs stated that having established relationships with patients was important for having difficult discussions throughout their illness and knowing what type of language could be used with patients:

it makes a huge difference knowing them and taking care of them for a while and then when you ... when you're there for them at the start of a diagnosis and you also see how bad things are becoming - they understand how it is.

One GP said that discussing plans for end of life care were made more difficult if the patient wanted to keep certain information private from family members. The GP stated that this ban on communication meant it was difficult to know what support would be needed at home:

It's much easier when they come with their partner. Problem comes then, if they're very particular they don't want their partners to be involved because then you need to get word how they're going to cope ... and how their partners are going to cope when we don't know what exactly they know.

Likewise, the same GP also said that having relatives involved in discussions appeared to have benefit for the bereavement process for both relatives and patients:

I think so because not only gives the relatives that we are doing all we can, but it gives them closure when the patient dies because they know they've done what had to be done and they know the patient has died peacefully, not in pain. It's very important for the relatives and so is it for the patient, because sometimes they feel they're leaving behind people in such a state so that gives them that closure for the patient too.

However, it was also felt that better bereavement services were needed for carers.

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?

The GPs cited a number of methods that made discussing end of life preferences easier or methods they believed could potentially make it easier. Firstly, it was felt that more training would be beneficial. Both GPs said they had palliative care training and experience and that this was beneficial to them, but that this experience was not widespread across primary care.

I think having more palliative care training as standard in GP training would be a good thing. I didn't actually have a formal palliative care block in my GP training but I was at a training practice that had strong links with St Christopher's Hospice, so I did feel trained up in it, but from medical school there was little palliative care training after that.

It is partly having 2 doctors in the team who make palliative care their special interest so the processes are quite well set up here.

One GP said that training healthcare professionals to monitor their own emotional well-being would be useful as end of life discussions are emotionally draining on the healthcare professional as well as the patient.

it's OK to use those dying words, it's OK to feel drained, it's OK to feel emotional after a consultation because you've got to take care of yourself too.

Another way to make having discussions easier was to improve record keeping thus improving the information available to care providers. One GP said it was useful to have a common template that different healthcare professionals could consult to see whether patients have already discussed preferences which would make updating preferences easier.

I think it is important and it's very helpful and if a doctor can look back in the notes and see clearly somewhere, 'Oh you've had this discussion' - it's a great way of introducing it. 'I see that when so-and-so spoke to you in' you know, whatever the date it was, 'you said that you thought your preferred place of death would be at home. How do you feel about it now?' It's an easy way of introducing it so if it was part of the standard history summary that you have on the front sheet, it would just make it quite easy for bringing it up in conversation.

Both GPs stated that problems for care planning arose when patients got mixed messages from the hospital about their condition. This made discussing end of life issues harder because patients did not understand their prognosis or have a clear understanding of treatment options.

That's where the huge problem comes actually. And so just thinking about the patient I had a conversation with last week - they're still getting very mixed messages from the hospital about whether their condition is curable... And so we had the discussion but there was interspersed was, 'But we are waiting because I'm going to see the consultant again and he says he may still be able to operate' and I think there is a great tendency not to tell people there's nothing more than can be done at the hospital until it gets to crisis point.

Referring non-cancer patients to the hospice was difficult because patients commonly perceived that the hospice was only for cancer patients. It was felt that the hospice could be more proactive in advertising itself as a place for end of life care rather than end of life *cancer* care.

there are chronic illnesses where we can't do anything and those patients, I think are much more... there are hospices opening up for them much more is the answer to that, so it's nice because they can make things a little more comfortable for them but the question is are they willing to accept because that is still a difficulty which I see because patients are not coming to terms with it. You know, if they're not dying. They are dying but in their mind they are not dying of cancer so they shouldn't be going into a hospice so probably the hospice needs to... and we, as professionals, need to advertise that it's not only for cancer.

Both GPs highlighted the importance of multidisciplinary working and saw their role as a central point for the patients' care. GPs are there to discuss options throughout a patient's illness and refer the patient to various services to meet their needs.

They go for hospital appointments and again, they're given the bad news where treatment has been done and they say they can't do any more and the next port of call will be the GP to discuss what else can be done.

I think if you're thinking about end-of-life care, if you don't have that seamless link between GP and district nurses, you're going to have difficulty managing end-of-life.

6.3 Assessment of the existing questionnaire

Assessment forms and care plans were kept electronically within the surgery, including questions pertaining to end of life care and wishes [see appendix 2]. The benefit of an electronic form means that anyone in the practice can easily find the relevant patient information should an issue arise and automated letters with selected information can be quickly generated. Also this information could potentially be accessed by other care providers if electronic systems were joined up. Patients could easily be given a copy of their wishes as discussed with the GP for their own records. A personal paper copy of the care plan kept at home might be useful to have should emergency services be called to the patient's house.

There are three coded options for preferred place of death on the electronic form: home, hospice and hospital. This list is overly simplistic and should be expanded to include: nursing home, cottage or acute hospital, and relative's home. It is also unclear whether a date is recorded for when the preference was made or if additional free text can be added; both would be advantageous. As in the care plan used by the nursing home in our study, it may also be useful to have ranked preferences.

The piloting phase was not utilised as it was not feasible to integrate a paper based form into the electronic system and it was not possible to alter the electronic system.

6.4 Discussion

GPs saw themselves as central to a patient's care, from diagnosis to end of life. They are a constant point of contact and resource in the patient's changing care needs. Because we were not able to interview patients, we do not know if this view was shared by patients. How central the GP is may depend on the patient's diagnosis whether cancer, COPD, renal failure or other and thus how involved other services are.

We identified five key themes in relation to discussing preferences from the point of view of the GPs: relationships with patients, changing wishes, patient knowledge, experience and training, and multidisciplinary working.

Relationships with patients

Having longstanding relationships with their patients was important to the GPs for helping patients to make decisions and express their wishes. Knowing their patients meant that they knew what sort of language they could use and the approach that they could take with the patient. This relationship was perhaps enhanced by the fact that GPs are involved in a patient's care from diagnosis to death and therefore they go through the journey of the patient's illness with them. The nature of the relationship between GPs and patients in identifying illness and exploring treatments means that the dialogue of preferences and choices is constantly evolving. Therefore creating a questionnaire with ordered questions may not be appropriate for the way GP sessions are conducted. It seemed that the GPs adopted a gradual approach to discussing difficult issues, though this may be related to their additional training and experience in palliative care.

Changing wishes

The GPs were keenly aware that patients wishes changed over time as their illness progressed. GPs may be more aware of changing preferences because they are involved in the patient's care from when they are fairly well to very ill; whereas hospices and hospitals may only be involved in acute phases of the illness. Despite this awareness of changing wishes, one GP was keen that all patients should discuss end of life wishes upon reaching a certain age, much like specific diseases are screened for as patients age. This tactic may not be particularly useful as patient's wishes at an early stage may not reflect the experience of acute illness, though introducing preferences as a topic early on may help to generally desensitise patients to future discussions.

Patient knowledge

One GP stated that patients 'should not be in denial about their condition' as this made discussing options difficult if not impossible; this supports findings from the literature (Borreani *et al*, 2008). Therefore accurate and understandable communication from healthcare professionals which patients understand is extremely important, especially as multidisciplinary working is very important for end of life care delivery. When patients receive mixed messages it makes it difficult for other members of the care team to carry out the assessments that are necessary. This is particularly salient to discussing end of life preferences as patients may be more unwilling to discuss end of life care if they are still hopeful of curative treatment.

Experience and training

Both GPs cited their experience of working with palliative care patients and interest in palliative care as important for making them more comfortable with the subject. They recognised that palliative care training is not widespread across primary care, even though end of life discussions are seen as 'bread and butter' of primary care.

GPs and multidisciplinary working

Close relationships with other care providers were important for exchanging information and providing seamless end of life care for patients. The GPs saw themselves as a central point for referring and managing patient care. Ultimately when treatment ends or is ineffective patients are referred back to the GP for the next step. Therefore they must have accurate records of what other care providers have done and what has been discussed with the patient. Knowing what other providers have discussed made it easier for GPs to pick up the discussion.

One GP stated that the term 'hospice' was a stumbling block for some patients in that they perceived it as a place of death. This common misconception came out in phase 1 of the study on hospices. The GP said she told patients that not all patients go to the hospice to die and that it could serve other functions, such as symptom management. It was felt that the hospice should do more to change this stigma, though as a referrer GPs should be explicit with patients about the purpose of the hospice.

The GPs both stated that they felt that hospitals did not communicate effectively with patients about their condition. One GP suggested that this was likely because healthcare professionals, particularly in hospital do not want to give patients bad news. It is also complicated by the fact that hospitals are seen as a place of healing and if one treatment does not work then doctors may suggest an alternative, though they may not believe that it will be effective. Whether or not patients understand this is a different matter and this will be further explored in the next section on secondary care. From the GPs' point of view it seemed that they felt that the hospital was not

effective in delivering accurate information to patients about the status and treatability of their condition.

6.5 Recommendations

Firstly, the flow of information between care providers could be improved to include both factual and narrative information. Currently, GPs receive mostly factual information, particularly from hospital, but narratives about the patient's reaction, acceptance and understanding of a diagnosis or prognosis may be useful to GPs. What has been discussed with the patient should be in a uniform structure and shared routinely between providers. This could potentially be in the form of a standardised letter, though the transfer of information would need to happen quickly prior to or at the point of discharge. Also, if GPs discuss issues with the patient, such as clarifying a prognosis or diagnosis with a patient, this information could then be relayed back to the hospital consultant who could then confirm what the GP said with the patient. Confirming that what the GP said is correct may help to reassure the patient that all care providers are aware of the patient's condition and may help stop the 'mixed messages' that come from the hospital.

Secondly, the existing questionnaire could be altered to include more options for the patient as discussed in section 6.3, or alternatively a free text area instead of pre-coded responses. This may be more inclusive of all scenarios as the GPs acknowledge that preferences are likely to change over time and free text areas would allow patients to express more complex statements that might cover longer periods of their illness.

Finally, standardised training for GPs in how to deal with palliative care patients would be beneficial for both patients and healthcare professionals. Experience is likely the best method for learning how to deal with sensitive subjects, but for new GPs this is not an option. Learning how to deal with the emotions of discussing death and dying would perhaps have a preventive character for the health of GPs.

7 Secondary Care

7.1 Participants

Interviews with a physiotherapist and ward nurse and one group interview with two registrars were conducted in a hospital in East Kent. Participants were recruited by one of the participant registrars. One researcher conducted the interviews with the physiotherapist and ward nurse and a second researcher conducted a joint interview with the registrars. Interviews were conducted whilst participants were on duty in the emergency care centre. Participants cared for a wide range of patients on different wards, from older people to emergency care.

Our key contact who arranged the interviews felt it was not possible to conduct interviews with patients due to their frailty whilst in hospital. We were not able to organise interviews with carers within the project time frame.

7.2 Findings from the Interviews

Do you usually ask patients with life-limiting conditions where they want to be cared for when they are dying?

There was agreement among participants that it was primarily the responsibility of the doctors to discuss end of life choices as they had overall responsibility for the patient's care:

... it should be everybody's responsibility but I think when it comes to discussions like that, professions like physiotherapy and sometimes nursing feel it's a discussion that the doctor or the person in charge of that patient's care should have, so we'll leave it to the doctor to do, rather than do it themselves or take it upon yourself to say, you know, to bring up that subject.

Because of the sensitivity and the time required to have these conversations, doctors made appointments with patients outside of ward rounds to have the conversation rather than have it spontaneously:

A lot of these discussions which are fairly difficult can't be performed on the emergency department, they can't be performed on a time-limited ward-round so it's down to ... the registrars or the consultants to make appointments away from these times to see patients, to see families and to formulate some sort of decision. I'd say I spend 3 out of 5 afternoons having these sorts of discussions with all sorts of patients, not just patients with end-of-life needs.

Planning for discharge begins at admission, and therefore doctors tried to have discussions around choices for end of life care as early as possible in the patient's stay:

It's sooner rather than later really because well, we're in the habit of planning discharges at the time of admission and in order to do that, you need to know what the patients' wishes are.

Though doctors wanted to give patients choice it was felt that options available to patients for end of life care were constrained by the needs of the patient and whether these needs could be met at home or in an institution:

I think in some cases it's difficult because the patient has needs that can only be met within an institution, so those needs might be comfort needs, in which case they might need to go into a hospice. At other times their needs might require nursing care, so 24 hour care might be an option. If the patient is well with a terminal illness, with no symptom needs then we do discuss where their desired

...discharge destination would be; in fact, we discuss that with every patient, whether they have a terminal illness or not.

The nurse and physiotherapist said they would usually only discuss end of life preferences with patients if the patient brought it up. Firstly this was because end of life and prognosis conversations were seen as the responsibility of the doctors or the palliative care nurse. Palliative care patients, mainly those with cancer, were usually referred to the palliative care nurse to deal with:

Judy is our Palliative Care Nurse and she is called to see people when they are dying, you know, and she is very clear about what she can and can't facilitate and documents clearly all discussions that she's had with people so I think we tend to leave it to her and she is sort of the lynch-pin in the hospital for these things and she will help make decisions.

One of the registrars also stated that sometimes she deferred end of life discussions to the palliative care teams:

we tend not to discuss things about where, you know, prognosis necessarily with them because palliative teams will get involved.

The second reason for not having end of life discussions was that the nurse and physiotherapist were often not sure how much the patient knew about their prognosis and were therefore afraid of divulging information which was not known to the patient and thus upsetting them.

I try and be as honest as I can be but I think you always have this sort of little cloud at the back of your mind saying, 'what do they know and what don't they know'. I think that's the trouble and 'am I going to say anything that's completely ...' you know.

What kind of language do you use when discussing death and dying?

As in the other settings, the language and approach that healthcare professionals used was guided by the type of patient they were dealing with and they tailored their language to that patient. The way preferences were discussed was also dependent on how well the patient was.

It depends on the patient. It depends on sort of what they've said to you already or what the family have said to you, or what ... you know, how unwell they are.

As hospitals are often the front line when determining diagnosis and prognosis, it was important for doctors to clearly communicate to the patient the severity of their illness. Therefore doctors stated that there came a point where they had to be explicit with the patient even if the patient was uncomfortable with the conversation.

There are patients who talk about their illnesses as if they are non-tangible so I had a patient call liver cancer a 'gremlin' but there are patients who talk about their diagnoses like, 'I know I have cancer. I know it is killing me' and depending on whether you've got the 'gremlin' or 'cancer patient', you tailor your discussion and your language to them, which theoretically we shouldn't be doing, but practically we have to do... .. And like I said with patients who talk about their cancers as 'gremlins', there comes a point where you've got to say, 'Actually this isn't a gremlin – this is a cancer and we're not going to be able to cure it so how are we going to take things forward?' you know. That sort of gets ... it's a huge sort of ... you either get, 'I don't want to talk to you any more' or you get, 'OK'. And you never have those discussions with patients just on their own, you have them with their family stood right next to them so you can give them the opportunity to say, 'I'm going to go out for 5 minutes and then I'll come back and we'll talk about this some more', because there always comes a point where you've just got to be explicit.

How comfortable do you feel discussing dying with patients and their families?

The participants varied in how comfortable they felt in discussing dying with patients with some saying they were comfortable with the discussion and others saying they were not. Particularly difficult was telling a patient that they were dying, especially if it was unexpected. The two registrars differed in their comfort level:

I'd say ... I wouldn't say very comfortable because it's never a very easy discussion. I would ... personally I would say I'm quite comfortable ... actually reasonably comfortable.

I'm uncomfortable. I spent 15 minutes psyching myself up to bracing bad news to a patient only last week and that was only because it was unexpected, so I think I was uncomfortable in that situation to say to the man that I think he was dying. I did it, but I sat at the desk and I said, 'You must do this now. You must get this done. This must be done' and I realised afterwards that I'm just not as comfortable as I thought I was

The physiotherapist attributed her discomfort with discussing dying to her lack of experience with having such conversations.

I don't find it terribly easy because I don't do it a lot and I don't think in my job that we need to ... well, we don't seem to be asked to be involved with those sorts of discussions an awful lot; I think other professions are a lot more.

As stated previously, the physiotherapist also found these conversations to be more difficult as she often did not know how much the patient had been told about their condition by medical staff. She also said that she perceived that often patients intuitively knew when they were dying and in those cases she did not need to reiterate what the patient likely already knew.

One of the registrars said that she was more comfortable with discussing dying with the patient's family, perhaps because the family is removed from the patient's situation.

I'm very comfortable with families though. If it were the family, I can rationalise it to them, you know, and I'm comfortable about sort of saying, 'This is unfortunate news but I think you must know', and so I tell them. But to look a dying man in the eye and tell him he's dying; that's terrible.

How is information about what has been discussed with the patient communicated to the GP?

Information about a new diagnosis, prognosis or treatment received whilst in hospital that was passed on to the patient's GP tended to be quite factual and clinical rather than elaborating on the patient's understanding of their prognosis. What information was passed on may have depended on the attending doctor or patient characteristics.

Interviewer: In your discharge [notes] do you tell the GP that you've had a discussion with a patient about the life-terminal condition they have?

Registrar: It's hit and miss and I don't think that information is actually included in the discharge summary. It is very factual...

7.3 Assessment of the existing questionnaire

The hospital did not use a standard form for recording patients' end of life wishes. Any such discussions and decisions were recorded in the patient's notes. As end of life discussions would not be appropriate for many patients in the hospital, it seems reasonable that it is not included as part of the standard form. However, if patients are assessed as having palliative care needs then perhaps

there should be a standard form or section of the care plan which could be used to inform other care providers of relevant information. Hospital staff may not feel it is appropriate for them to have end of life discussions if the patients are not at that stage in their illness or they may not be aware of all the options available in the community. However, they certainly have information which would be of value to GPs or district nurses who might then have such conversations. The following information might be of use to GPs and could potentially be included in the care notes in a standardised narrative format:

- patient's understanding of diagnosis,
- patient's understanding of prognosis,
- patient's understanding of expectations of any planned treatment,
- whether diagnosis and prognosis have been discussed with the carer/family,
- whether the patient's wishes for end of life care have been discussed.

Having this information structured in a standard way rather than embedded in care notes would help draw the GPs or other care provider's attention to it. In some cases this information might be given verbally to the GP when the patient is discharged and handed over to the GP. However, having a written summary of the above information would ensure that all care providers with access to the care notes have this information available to them.

7.4 Discussion

Firstly, it should be said that the participants generally did not seem to have long-standing relationships with most patients. Participants generally cared for patients during an illness episode, rather than over the long term.

Responsibility for end of life discussions

Though the doctors were identified as primarily responsible for discussing end of life preferences, the palliative care nurse was also cited as a primary professional to deal with end of life issues. However, this recognised responsibility did not mean that doctors were any more comfortable with the discussion than those who did not see it as their responsibility. Nursing staff felt that they should only discuss end of life care if the patient brought it up as they did not see themselves as in a position to take on the discussion. This was largely because they were not always certain of what the patient had already been told and what they understood.

Uncertainty in patient knowledge and understanding

Though it may have been clear among the interviewed participants who was responsible for having end of life and prognosis discussions, it was not always known to the nurse and physiotherapist what was discussed in meetings with patients or how much they have understood. Patients were usually quite unwell in hospital and how well they had understood the information they were given was questioned by both nursing and medical staff. The nurse and physiotherapist seemed to be concerned about upsetting patients by talking to them about something they had not yet been told. It was not clear whether this fear came from past experiences, or a perception that this might happen and possible consequences. This fear may also simply reflect the cultural taboo of discussing death. However, it does seem a reasonable and sensitive approach to not repeat a discussion about death if it has already been discussed by others.

As suggested in the literature, a stepped approach to conveying information in hospital might be particularly useful as patients may have little knowledge about their condition prior to the hospital

episode. A stepped approach builds on what has already been said rather than 'blind siding' the patient. Having room to record patient's reactions and feelings in the care notes as suggested in the literature may be very useful for when patients are referred to other professionals.

Treatment focus

The focus in hospitals is generally on treatment and improvement. Staff stated that they must respond clinically if patients present in the emergency care centre even if they have a terminal illness. This has implications for patients who have chosen to die at home. A terminally ill cancer patient may come into hospital with a chest infection but die of cancer in hospital while being treated for the chest infection. Focussing on the problem at hand may mean that discussions on end of life care may be left too late if they are not seen as relevant to the condition being treated. Patient wishes previously expressed may only be known if they are given as part of the patient's history which is taken at intake or in the ambulance. However, one nurse did say that decisions would be taken not to resuscitate a patient if it was felt that their quality of life would be compromised.

Communicating patient understanding to primary care

Transferring information about the patient's understanding of their condition was not just an issue for staff within the hospital. One registrar reported that information sent to the GP on discharge was mostly factual with little information about the patient's understanding or acceptance of their condition. Not all doctors will have been able to speak with the patient's GP before the GP sees them. This could potentially pose problems for the GPs as they have to guess as to what the patient knows and understands.

7.5 Recommendations

Firstly, better communication between medical and nursing staff is needed so that all members of care team are aware of what the patient has been told whilst in hospital. However, participants also indicated patients did not always understand what they were told. In addition, patients may have unrealistic expectations of treatment which creates pressure on doctors to deliver good news. These factors might contribute to the miscommunication that can happen between doctors and patients. Information about what has transpired during these discussions should be shared routinely within the hospital care team and would also likely be useful to GPs and other members of the multidisciplinary care team. Sharing such information may help to ease the transfer of care and improve integrated care planning across primary and secondary care. However, there is a growing trend in hospitals to discharge patients with a copy of their care summary that is also sent to the GP. Therefore hospitals would need to be careful of what type of subjective comments about patients' understanding of their prognosis are included in the summary.

Additional communication training for nursing staff could be utilised so that non-medical staff feel more confident in what to say to patients who wish to discuss their end of life wishes. This could be useful in both situations where patients have been told their prognosis as well as for those who have not yet spoken to the doctor about their condition. It seemed that doctors would also benefit from additional training on how to communicate effectively with patients as well as how to emotionally cope with having distressing discussions with patients.

8 Comparisons and observations between the settings

In this section we take a wider view of themes across settings and try to position our findings in the wider local context. We have also drawn on findings from the hospice phase to help fill in details where possible to give a rounded description and hopefully a more realistic account of how preferences are managed across settings.

In all three settings there was consensus that doctors are responsible for diagnosis and prognosis discussions, even though it was acknowledged that all healthcare professionals should be responsible for end of life care discussions. The greatest hurdle was to tell patients they were dying and to help them accept that fact, after which discussions pertaining to dying could become easier. Once these initial difficult issues were discussed, other care providers were able to discuss care planning options as they related to their area of expertise. GPs in particular saw themselves as responsible for discussing end of life options and wishes. Though doctors in secondary care recognised that they should be having end of life discussions, the GPs' perception was that doctors in secondary care were not effectively communicating the reality of the patient's condition and options with patients. It is likely that if end of life decisions were relevant to planning discharge or care planning then this would be discussed in the secondary care setting. However, even in these situations such discussions were usually deferred to a palliative care specialist- a person who has greater experience with end of life matters. There is a general perception that hospitals are for getting better, not dying and thus messages coming from healthcare professionals in hospital may be perceived by patients in a way that supports this convention.

The emotional experience of giving bad news and having end of life discussions was described as a challenging professional task. This was particularly so where news was unexpected or if the patient was relatively young. It may in part be that discussing end of life choices with a patient brings a doctor's own mortality to the fore. There are two potential ways to reduce the emotional burden placed on doctors. The first is to increase and improve training that doctors receive in how they both relate to palliative care patients as well as how to handle their own emotional response to the situation. Secondly, more detailed records and shared communication between healthcare professionals across care boundaries might help to create a dialogue about end of life wishes that could be built on by all care providers. If each healthcare professional works towards clarity and understanding with the patient, then there is less for the next healthcare professional to do. Good documentation would also mean that discussions are not duplicated as this may distress the patient.

Documentation of patients' preferred place of dying varied across each of the three healthcare settings. Record keeping of patient preferences was better developed where patient caseloads were more constant, i.e. the nursing home had very clear, consistent and complete records, whereas records in the hospital had more variable content. This may be a reflection of the patient-healthcare professional relationship as long-standing relationships might lead to more open discussion of preferences. It might also reflect the nature of illness in each of these settings and a changing rota of healthcare professionals providing care. Those in hospital might have a more evolving illness profile than those in a care home and might be seen by a multidisciplinary team.

In relation to the importance of the patient-doctor relationship, GPs generally were in a better position to discuss planning for end of life care. Nursing home staff were also in a better situation for this as the physical marker of entering the care home generally signified a transition in life which prepared the residents for having such discussions. As trust and security are necessary for such

personal discussions, those with greater access and longer relationships with patients may have greater ability to have such conversations. Where these types of relationships do not exist, if the information is clearly relevant to the patient's situation then this may be a substitute particularly if the information is delivered by a healthcare professional with a clear role in end of life care. Discussions led by a palliative care professional, such as the palliative care nurse in hospital or a hospice community nurse specialist, clearly indicate to the patient that their involvement signals a palliative stage in their illness. Patients may seem to get mixed messages from doctors in hospital because they have dealt with a doctor in a curative treatment context and it may be difficult for both the doctor and patient to transition their relationship into one of palliative care. Patients may also not be able to differentiate between treatments that are curative and those that are palliative as they both are meant to relieve symptoms. Having different care providers with different treatments may help to clarify things for the patient.

9 Limitations

This study was designed to be exploratory and small scale; it therefore has a number of limitations.

Firstly, despite our best efforts we had only a small number of participants in each location and patients and carers were not represented in two settings. This was not entirely unexpected as our literature search revealed that studies such as ours which include patients with life limiting conditions are few as they can be a difficult group to access. The reasons for not achieving our expected sample were: staff rotas which made participation in focus groups too difficult, lack of interest from potential participants, and not being able to identify suitable participants.

The study reflects the local situation and the organisations which participated were identified because they had a recognised interest in palliative care. Therefore our findings may not be inclusive of healthcare professionals who do not put a large emphasis on the role of palliative care.

Those interviewed in the hospital setting mainly cared for non-cancer, non-terminally ill patients. This perhaps meant that they did not encounter many end of life scenarios as you might expect to find in a cancer ward. However, this did give the study a wider picture of how terminal issues are dealt with in non-palliative care areas.

There may also have been a degree of gate keeping by healthcare professionals in accessing patients and carers. Healthcare professionals may have thought that there were no suitable patients or carers for participation. Healthcare professionals may have been reluctant to ask patients or carers for participation if they felt that this may cause additional distress or anxiety in an already difficult situation. This is an understandable assumption, however, we know from our work in the hospice setting in phase 1 that patients and carers may actually welcome the opportunity to make a contribution. For future research in this area, new ways of reaching patients and carers (possible in a more direct way) would need to be developed.

10 Conclusions

Recording practices of patient preferences for place of care when dying were inconsistent across settings. If recorded, preferences were usually found in the patient's care plan. Recording practices tended to be organisation specific so that other healthcare professionals within an organisation were familiar with the practice, but this practice may not transfer well to other settings. This was most notable with information flowing back and forth from the hospital. Standardised methods for identifying patients with palliative care needs and then taking steps to meet these needs could improve communication between settings.

This study supports previous findings in the literature of the importance of healthcare professionals having established relationships with patients for making discussions more comfortable for all involved parties. Not only is it important for healthcare professionals to know the patient, but also to know what the patient knows.

This study also supports findings that 'place of care' is not synonymous with 'place of death' and that the understanding of such a phrase is context dependent. Using patients' own words is a generally accepted way of broaching the discussion and for making it more palatable to patients.

GPs felt that the hospital gave mixed messages to patients, but reports from the hospital setting also suggest that actually it may be that the patient has not understood what they have been told. Without having spoken to patients, it is difficult to know whether the communication barriers lie with what information has been given or what the patient has understood. It could be a combination of patient and doctor misunderstanding, but it seems that all too often members of the care team are more aware of the patient's condition and available treatments than the patient is. This would then create the situation that was described by the nurse and physiotherapist in the hospital in which they were unsure of whether patients knew what the medical and nursing staff knew.

Difficulties in prognostication also make discussing end of life choices challenging. Doctors may feel that they cannot accurately make a prognosis and so therefore choose not to have end of life discussions until they are absolutely certain that a patient is dying by which time it may be too late for the patient to make arrangements for their death. Perhaps then, once a diagnosis is made of a condition that potentially will limit life, all possible outcomes should be discussed, including death. However, this may not be feasible since many patients will not want to consider death if they have not yet even sought curative treatment. Whatever the scenario, the aim should be to build a dialogue over time that prepares patients for the end of their life and all care providers should be included in this discussion.

We have focussed on preferences for place of care and death. However, it may be worth phrasing the question in terms of priorities at the end of life. Gomes and Higginson (2004) suggest that we better understand patient priorities at the end of life to understand why preferences may change, but perhaps simply meeting these priorities for end of life care will be more inclusive of patients as it may be that end of life patients do not care as much about where they are, but rather the circumstances that surround that choice. This is evident in a consistent use of qualifying statements that form a part of a patient's expressed preference. For example, many patients will say that they wish to be at home as long as they are not a burden to their carer. Therefore their priority at the end of their life is the well-being of the carer and their choice for place of death is second. A system of recognising and acting on priorities is of course difficult for services to respond to as priorities are subjective and may constantly be changing as situations develop. Nevertheless, preferences will still need to be recorded and effectively communicated between healthcare professionals.

11 Recommendations

There are a number of recommendations as learned from the research that span all three healthcare settings which we discuss here.

First, palliative care patients need to be given clear information about the options available to them for end of life care. They should have information about what services they can access and what the limitations of the services are. The pathway of care should be clear to both patients and carers so that the potential for confusion is minimised during crises and when the patient is nearing the end of their life. Uncertainty in the care pathway can lead to fear and potentially poorer bereavement outcomes. Documenting key pieces of information such as preferences and choices for service use and sharing such information could help with this.

Documentation for recording preferences should be improved to contain a wide variety of possible places of death for the patient. Limiting the places listed to home, hospital or hospice may restrict the discussion to these places when other options exist, such as nursing homes or cottage hospitals. As hospital is generally not a preferred option and hospice has a stigma attributed to it, patients may believe that home is their only option when in fact a nursing home may better suit their needs. Having a comprehensive list may also serve as an *aide-mémoire* to healthcare professionals to discuss all relevant options. If patients are really to be given a choice or chance to express a preference, then they must be aware of all possible options. Comments made by the healthcare professional or patient should also be contained within the notes so that other healthcare professionals can easily identify the ongoing dialogue between the patient and healthcare providers.

Good documentation as described above could then be easily transferred between healthcare professionals in different settings to improve communication. However, the drive for greater transparency in the NHS for patients may prevent such communication from being truly insightful. Though it may be useful for healthcare professionals, such as a GP, to have a full understanding of what the doctors in hospital have discussed with patients and the patients' understanding of this, it is not likely appropriate to copy such commentary to the patient. It is important that healthcare professionals have an understanding of what others have discussed with the patient so that they know where to pick up the discussion or what approach to take with patients, but expressing concern over the patient's acceptance of such information in the notes may not be appropriate as these notes may be copied to the patient. Personal phone calls between health professionals would be ideal, but perhaps not always practical. However, in such cases where patients are having a particularly difficult time coming to terms with a prognosis or care options are complex, then phone calls to other healthcare professionals should be made standard practice.

Training in successful ways to conduct end of life discussions and in how to deal with the emotional burden that these discussions may pose for healthcare professionals from all care settings is necessary and should be ongoing. Palliative care training is not standard across the settings involved in this study, even though each of the healthcare professionals had at some point encountered a patient with a life-limiting condition. Such training may help improve the rate at which preferences are discussed, recorded and monitored and also improve how healthcare professionals regard such discussions.

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Appendix 1: Copy of nursing home advance care plan

Advanced Care Plan for:		Room:
The people involved in this meeting are:		Date of Meeting:
The person speaking on my behalf is:		Their relationship to me is:
<p>1. Thinking Ahead These aspects of care are important to me and are what I would like to happen in the future:</p>		<p>2. Proxy / Next of Kin The persons I would like to be consulted about my care if I become unable to make my own decisions are:</p> <p>1.</p> <p>This person does / does not have Lasting PoA Personal Welfare</p> <p>2.</p> <p>This person does / does not have Lasting PoA Personal Welfare</p>
<p>This is what I do not want to happen to me:</p>		<p>3. Preferred Place of Care If my condition deteriorates in the future, the place where I would most like to be cared for is:</p> <p>1st Choice:</p> <p>2nd Choice:</p>
<p>I do / do not have a Legal Advanced Directive</p>		
<p>4. The special requests and wishes I have following my death are</p>		<p>5. My views on resuscitation (heart suddenly stops) are:</p> <p>Refer to GP: Yes / No</p>
<p>Signed (Resident)</p> <p>Signed (Representative(s))</p> <p>Signed (Staff)</p>		<p>Date:</p> <p>Date:</p> <p>Date:</p>

Adapted from Care Standards Framework Care Homes Advanced Care Plan 2005

Appendix 2: Copy of primary care electronic proforma

Template For	[V]Palliative care	Classification Code	Appears in	()
Prompt		Age & Sex	Coded	Subsets
[V]Palliative care	(ZV57C)	0-140		
Excep	report:	pal	car	qual ind
(9hB)		0-140		
			Exc pal care qual ind:	Pat uns (9hB0)
			Exc pal care qual ind:	Inf dis (9hB1)
Pain Score	(PA3)	0-140		
Nausea Score	(NA1)	0-140		
Sedation Score	(SE3)	0-140		
Constipation Score	(CO1)	0-140		
Palliative	care		plan	review
(8CM3)		0-140		
Preferred	place		of	death
(94Z0)		0-140		
			Preferred place of death:	home (94Z1)
			Preferred place of death:	hospice (94Z2)
			Preferred place of death:	hospital (94Z4)
Pain	Management		Plan	Given
(PA9)		0-140		
Social/personal				history
(13)		0-140		
			Has Social Needs	(EMISQHA2)
			Has No Social Needs	(EMISQHA3)
Has a carer	(918F)	0-140		
Carer's details	(9180)	0-140		
			Lives in a nursing home	(13F61)
			Care from friends	(8GEB)
			Other social care NOS	(8GEZ)
			Does not have a carer	(918V)
			Care From Relative	(CA1)
Carer support	(807)	0-140		
Out	Of		Hours	Handover
(OU2)		0-140		
Removed	From		Palliative Care	Register
(RE12)		0-140		
[V]Palliative care	(ZV57C)	0-140		