Advance care planning in advanced cancer – can it be achieved? A patient preference trial of a care planning discussion.

April, 2009. Prepared by:

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Executive summary

We present the findings of a patient preference feasibility randomised controlled trial of an advance care planning discussion intervention for patients attending out patient oncology clinics with recurrent progressive cancer.

Our intervention was based on phase I work and consisted of up to three discussion sessions with a trained mediator. Discussions were standardised and focused on discussing the future with health professionals and close persons, the dying process, preferred place of care, identifying coping mechanisms and making future health care decisions. All discussions were audio-taped, transcribed verbatim and analysed qualitatively for thematic content.

Recruitment to the trial was restricted by the vigilance with which clinical staff assessed and referred patients to the research team. Patients were only approached if clinicians judged them to be ready for such discussions of future care. One hundred and eighty patients were approached by the research team of whom 78 agreed to take part.

All participants recorded their preferences for and against the intervention and two preference arms (to receive the intervention or usual care) of the trial remained open until 20 places had been filled. The remainder of the sample was randomised to the ACP intervention or usual care. Follow-up was at 8 weeks. Measures completed at baseline and follow up included visual analogue scales to measure communication with healthcare professionals and close persons and satisfaction with care, the Hospital Anxiety and Depression Scale (HADS) and completion of advance directives. Attrition to the trial was very low.

As expected, due to the low numbers recruited to a feasibility trial, statistical analysis of outcome measures showed no significant differences between the preference, randomised or combined groups. However, assuming that a statistical level of significance of 0.2 indicates an important trend, patients in the preference cohort receiving the intervention showed less satisfaction with communication with professionals and lower general satisfaction, coupled with a higher likelihood of having had advance care planning discussions with professionals. These findings may suggest that expectations were raised in the group receiving the intervention and might imply that the ACP discussion sensitised each patient to how much communication could be improved. There was no effect on anxiety and depression.

This study is ground breaking in that it reveals qualitative data on the topics that patients discuss during ACP discussions. The data are presented in detail in the full report and show the wide variation in readiness of patients to address issues relating to future care, including death and dying.

We conclude that it is possible to conduct a trial in this sensitive area without causing measurable distress. Not all patients are ready or willing to discuss issues of advance care planning even when their disease has recurred and related issues are already in their minds. Outcomes for a larger scale trial might include monitoring the frequency and content of patient/clinician discussions concerning future care. Our study provides important evidence that should be considered by those preparing policy and guidance documents for professionals working with patients with advanced cancer.
1. Introduction

In this report we present the results of a phase II exploratory patient preference trial of an advance care planning (ACP) discussion for patients with advanced cancer. It builds on published qualitative phase I work conducted by the same group (Barnes et al., 2007). ACP is of increasing interest and importance in the UK as numerous recent policy documents have recently recommended its use. However, there has been very little research in UK to provide evidence to support such an approach.

1.1 Policy documents – published since start of this research

The Cancer Reform Strategy (DH, 2007) builds on the information published in The NHS Cancer Plan (DH, 2000). In considering ACP, it recommends face to face support for patients and access to quality information to enable patients to make informed choices. Whilst considering that ACP may allow patients to regain a sense of control over their lives, the strategy recognises the need for health professionals to be aware that not all patients wish to make decisions about their care and that some wish to adopt a more passive role. It acknowledges that ACP conversations should proceed with sensitivity, taking care to assess how much the patient understands, wishes to know and wants to involve other family members, and recommends that any decisions reached should be reviewed with patients at regular intervals.

The End of Life Care Strategy (DH, 2008) supports the principle of ACP as a helpful way of finding out patient preferences about the care they would like to receive at the end of life, and calls for more research on all aspects of end-of-life care including ACP.

In order to encourage consideration of ACP for those with advanced illness, the Gold Standards Framework (GSF) has been developed as a tool for use in primary care by which patients at risk of death within 12 months are identified and offered ACP. GSF is a framework of strategies that assist primary care teams to deliver the best possible care for patients approaching the end of life. It recommends that ACP discussions take place in primary care with the patient and family/carer that these discussions are documented in the patient records and are repeated at intervals to enable a developing relationship of trust and openness between staff, patient and their families or carers. To aid the conduct of such discussions, a guide entitled Planning for your future care has been published on the Gold Standards Framework web site (7th April 2009). This builds on guidance published in 2007 and revised in 2008 by the National end of Life Care programme (DH) and the University of Nottingham entitled Advance care planning: a guide for health and social care which clarifies the definition of ACP as a process of discussion between an individual and their care providers irrespective of discipline. ACP discussions differ from a standard care plan in that they usually centre on the future and an individual’s wishes were they to lose capacity. An ACP discussion might include the individual’s concerns, the important values or personal goals for care, their understanding of their illness and treatments that may be beneficial. The document does not recommend a standard format for recording an ACP discussion, but suggests notes be made as this may prove useful in the future. A person might make a list of wishes and preferences for their future care, which may be about future care preferences or may explain their feelings, beliefs and values that govern how they make decisions.

In addition, this year the Royal College of Physicians has published Advance Care Planning – National Guidelines (2009.) This document acknowledges the variable nature of the process and the need for sensitivity and care in the conduct of discussions which should be undertaken only by those with appropriate communication skills. All ACP discussions should be voluntary, occur at an appropriate time for patients and that they should not be initiated as routine care or from outside pressure such as family wishes.
1.2 Literature on ACP

The majority of research on ACP supports the view that patients dislike being approached with a checklist of consent for specific treatments but prefer discussions about ACP based on their values and experiences of illness (SUPPORT, 1995; Brown, 2005). Many patients have been reported to prefer to discuss treatment preferences with family or surrogates rather than with their physician. An investigation into the willingness of cancer patients, healthy controls and medical staff to write an advance directive found that only a minority of participants had written an advanced directive or knew about the possibility of appointing someone as a health-care proxy. Half of those surveyed feared that patients could be pressurised into writing an advanced directive and 38-65% feared that relatives could abuse such documents (Sahm et al., 2005a). This study also examined adherence to advance directives in cancer patients and healthy controls. The findings suggest that both groups disregarded instructions laid down in the documents and did not consider them as binding as medical staff. The authors conclude that advance directives may only be beneficial to a limited few who choose to reject certain therapeutic measures and that ACP as a less restrictive method should be considered (Sahm et al., 2005b).

A retrospective comparison of the association between advance directives and quality end-of-life care was conducted with bereaved family members. They reported the completion of an advance directive was associated with fewer concerns with communication (Teno et al., 2007). Question prompt lists have been used with advanced cancer patients to facilitate asking questions about prognosis and end-of-life care. They were found to assist cancer patients to ask questions and engage in discussion but importantly did not increase anxiety or impair patient satisfaction (Clayton et al., 2007).

A systematic literature review was conducted to assess interventions to increase advance directive uptake (Jezewski et al., 2007). The studies included in the review were conducted in Canada and the USA and assessed a wide range of populations, including patients with HIV/AIDS, chronic illness and serious underlying disease. Results showed that the interventions fell into two groups with one group using purely didactic methods (such as information through education) and the other using an interactive approach (person to person interaction). The didactic approach did not result in any increase advance directive uptake. A similar review most recently by Bravo et al. (2008), evaluated the effectiveness of interventions to increase advance directive uptake amongst older adults. The review looked at studies from the USA, Canada and Australia. They concluded that provision of oral information given over multiple sessions is the most effective type of intervention regardless of the population. In the UK, one study has shown positive results (Horne et al., 2006). This study developed and piloted an ACP intervention for nurses to use in discussing preferences and choices with patients with inoperable lung cancer. Although patients’ responses to the subject varied greatly, they did welcome the opportunity to document their wishes and preferences and appreciated the courage of the nurses for bringing up future care with them. The authors suggest that further larger scale research is needed to determine the components of ACP discussions.
2. Rationale for the trial

2.1 Phase one work on advance care planning (ACP)

Prior to this study, we began our work in this area in 2006 by conducting a small scale qualitative study with current patients in oncology and palliative care, carers and members of the North London Cancer Partnership Group (users) (Barnes et al., 2007). We held eight focus groups each consisting of 4-6 participants. The groups were led by a palliative care physician (LJ) and a research nurse (KB) and a palliative care clinical nurse specialist was present to deal with any distress that may have been caused to participants. In the focus groups, we reviewed a draft advance care planning discussion schedule, derived from pilot work (Shah et al., 2006), and explored the suitability of such discussions, their timing, nature and efficacy. The schedule included an assessment of previous experiences of care, current clinical and personal circumstances, and anticipated events and the fears these raised.

Participants felt that advance care planning should be conducted over time, with the advance directive being one component of a much broader discussion about end-of-life issues. Discussions should not be initiated too early but after recurrence or when the prognosis becomes poor, should be tailored to meet the specific needs of the individual and delivered in an atmosphere of trust and confidence with sufficient time available to talk through issues as they are raised. Exploration of advance directives and living wills revealed that although many participants were unfamiliar with this language, they understood the concepts. Participants found it helpful and interesting to talk with others in the focus groups and some were prompted to reflect further on their own circumstances and talk with relatives about their wishes.

Findings from this phase I work were used in compiling the ACP discussion schedule and topic guide that formed the structure of the intervention in phase II. We also used this evidence to select our ACP mediators to deliver the intervention.

2.2 Trial method

In an attempt to take account of the variation in patients’ needs and readiness to discuss ACP, we chose a patient preference design. The design took account of the sensitive nature of the research, variation in views of participants and was respectful of their autonomy. It provided information about the use of ACP both in patients who chose the intervention and also in those who declined. In this way we hoped to gather valuable information about the external validity of the trial (King et al., 2005) and also to learn about the spread of patient preferences within our study population and how these might affect outcomes.

Theory of patient preference trials

The efficacy of health and social interventions is best assessed in randomised controlled trials (RCTs) in which the average treatment effect, uncontaminated by confounding, is estimated (Sackett et al., 1996). Differences between treatment arms meet statistical assumptions by behaving like the differences between random samples from a single population (Altman & Bland, 1999). Participants’ and professionals’ preferences for interventions, however, affect the internal and external validity of RCTs (Cook & Campbell, 1979). A preference is "a disposition to respond favourably or unfavourably to an object, person, institution, or event" (Ajzen, 1988). Interest in patient preferences in context of RCTs has concerned the impact of preferences on external and internal validity (Cook & Campbell, 1979). Trial populations may be unrepresentative of those to which the results are applied and estimates of effect may be inaccurate if capacity to benefit differs in trial and non-trial
samples. Partial randomisation, or patient preference trials, is one answer to this problem. Only participants without strong treatment preferences are randomised. Those with preferences are allocated to their preferred treatment and followed up under trial conditions. Such trials are useful when treatments cannot be masked such as psychotherapy (King et al., 2000), other complex interventions (Gossop et al., 1986; Henshaw et al., 1993; McKay et al., 1995) or where agreement to randomisation is likely to be low (Chilvers et al., 2001). They also provide the opportunity to conduct more patient-centred research (Stewart et al., 1995; Dowie, 1996).

**MRC framework for the development of complex interventions**

This study comprised phase II work according to the MRC framework for the development of complex interventions building on our phase one work (Barnes 2007). The four steps of the MRC framework are: (1) Pre-Clinical or theoretical phase; (2) Phase I or modelling; (3) Phase II or exploratory trial; (4) Phase III or definitive trial; (5) Phase IV or long term surveillance.
3. Methods

3.1 Research questions

The aim of this study was to conduct a phase II trial of an advance care planning (ACP) intervention. Specific research questions were:

1) What is the acceptability and feasibility of a patient preference randomised controlled trial of an intervention to facilitate planning for end-of-life care?

2) Which outcomes are appropriate and measurable to assess the effectiveness of this intervention?

3.2 Study design

This was a patient preference randomised controlled trial. All patients entered into the study whilst the preference arms were open were given the opportunity to choose whether they would like to receive the ACP discussion or to continue with usual care. Patients could also choose to be randomised into the study and would then have a 50% chance of receiving the advance care planning intervention. We avoided pressurising or persuading patients in any way so that only those who were prepared to be randomised would be allocated to the randomised trial arms. On grounds of costs, we decided to cap the entry of patients into each of the preference arms of the trial at 20. As we were unable to give participants the choice of one preference without the choice of the other, once either of the preference groups reached 20, both were closed.

Figure 3.1 Study schema – patient preference trial

3.3 Study setting

The study was initially based in the Royal Free Hospital oncology outpatient clinics and the Marie Curie Hospice Hampstead. A year later the study was extended to oncology outpatient clinics at a second site, University College Hospital, to increase the number of eligible patients available for recruitment. Patients from all cancer specialities were eligible therefore the research team attended as many clinics as possible.
Oncology clinics attended at the Royal Free Hospital were those specialising in:
- Melanoma
- Liver
- Colorectal
- Breast
- Urology
- Lung
- Neuro-oncology

Oncology clinics attended at University College Hospital were those specialising in:
- Colorectal
- Urology
- Gynae-oncology

Clinics at both sites were consultant led and the majority also had registrars, research nurses and a clinical nurse specialist for each speciality. Some of the clinics would have more than one consultant. The clinics were attended by the research team regularly and where possible pre clinic meetings were the most appropriate times for clinicians to suggest eligible patients for the trial. Once patients had arrived for their appointments and were seated in the waiting room, the researcher would call out the patients' name so they could be identified, and then proceed to introduce themselves and the study. Introductions and discussions regarding the study took place in the clinic waiting room as there was a lack of available space to allow for use of a private room.

3.4 Introducing the study to clinicians

Before recruitment started at the two sites, oral PowerPoint presentations were made to the oncology staff to explain the rationale for the study, what the study would entail for the research team and for the patients, and what would be required from clinicians. We also arranged one to one meetings with clinicians to explain the study further and ask them to participate in facilitating recruitment. We also distributed information and a brief protocol to other members of the team such as research nurses, clinical nurse specialists and registrars.

3.5 Ethics

Ethical approval was given by the Royal Free Hospital and Medical School Local Research Ethics Committee on the 17th August 2006 (06/Q0501/93). The study gained site specific approval to recruit patients at a secondary site on 15th January 2008.

3.6 Patient selection

Participants were selected from outpatient clinics at the Royal Free Hospital (between February 2007 and September 2008) and University College hospital (between February 2008 and September 2008). Clinicians referred eligible patients to the researchers at the beginning of the clinics. The process of recruitment at the start of the trial required clinicians to introduce the study to eligible participants before the researcher met with them to talk in further detail. However, this required too much of the clinicians' time and as a consequence eligible patients were not being seen. Thus we changed the approach (with Ethics Committee approval) in order for researchers to approach eligible participants directly in the first instance with their clinician's approval.
3.6.1 Inclusion criteria

Patients were considered to be eligible for inclusion in the study if they:

- had completed a primary course of treatment, but still had clinically detectable, active, progressive disease.
- were considered well enough by the referring health professional to complete the advance care planning intervention
- were over 18 years of age
- were able to give informed consent
- had no psychiatric diagnosis
- spoke and understood English.

Shortly after the study was underway it was realised that patients with brain tumours were not suitable for recruiting into the study as they were changing neurologically from week to week. It was felt that under these circumstances it would be difficult to obtain informed consent.

3.7 Measures (see Appendix A: Questionnaire measures)

3.7.1 Baseline measures

Participants in all groups received the same questionnaires at baseline as follows:

1. Demographic details: age, sex, ethnicity, social class, education, religious affiliation and strength of spiritual belief, diagnosis and duration of disease

2. Measures prepared for the study
   a) Visual analogue scales measuring communication, satisfaction and discussing the future were measured from 0-10 on a sliding scale. This allowed for changes in the numerical score over time to be calculated.
   b) Three multiple choice type questions referring to whether patients had another health professional involved in their care, whether they had talked to another health professional about the future and also determining if patients had or intended to complete an advance directive document (see Appendix B: Terrence Higgins Trust Living Will)

3. Preference scale for receiving/not receiving the intervention
   Patients’ preferences were measured on a visual analogue scale. This was scored from -5 (strong preference NOT to receive an advance care planning intervention) to +5 (strong preference TO receive and advance care planning intervention), 0 was no preference either way.

   Participants could state their preference from one side of the scale to the other (0 equalled no preference). The preferences however did not define trial arm allocation as participants may have stated they had a strong preference for the advance care planning intervention but paradoxically still chose to be randomised.

4. Hospital anxiety and depression scale (Zigmond & Snaith, 1983)
   The HADS is a 14-item scale designed to measure both anxiety (7-items) and depression (7-items). It is designed to detect and assess the severity of anxiety and depression and has been used extensively as an indicator of psychological morbidity. Takes approximately 5 minutes for completion. The HADS was scored as recommended with each question having a numerical value from 0-3. These question scores were summed for an overall score, and
also split into the 2 domains of depression and anxiety. The HADS has good reliability and validity.

5. Karnofsky performance status scale (Karnofsky & Burchenal, 1949)
The Karnofsky scale was devised in the 1940s as an attempt to try and measure the more 'subjective' side of the outcome of cancer treatment. In fact the scale relates purely to physical ability and covers 11 points, from normal health to death, each scored as a percentage with ‘normal health’ scoring 100% to ‘death’ scoring 0%. Therefore if you have ‘normal health’ or 'minor symptoms' you are likely to tend to feel good, but if you are 'severely disabled' or 'very sick' you feel very low indeed). Over the years, more complex 'psychological' tests have shown that generally well being and quality of life match the physical scores on the Karnofsky scale. This scale has been shown to have good reliability and validity (Schag et al., 1984). This measure was completed by the researcher.

6. Qualitative information on reasons for preferences to receiving/not receiving the intervention

3.7.2 Follow-up
Patients in all trial arms were followed up 8 weeks after baseline measures and all groups received the same questionnaires at follow up excluding the preference measure. Qualitative information was elicited on the following areas:
- Participants’ clinical condition, any changes in health or medical treatment/care received since baseline.
- Participants’ views on the concept of advance care planning discussions.
- Participants’ views on the concept of advance directive documents.
- Participants’ views on their relationship and communication with close persons and health professionals, satisfaction with these relationships.

3.7.3 Consultants feedback
Feedback from consultants about referring suitable patients for the study

3.7.4 Research staff reflections
Researchers’ reflections on working with patients in a sensitive subject area.

3.8 Trial Outcomes

Primary outcome

Communication: Visual analogue scales measuring the degree to which participants felt able to discuss end-of-life planning with primary and secondary care professionals and close persons/members of the family.

Secondary outcomes

2. Psychological status: Anxiety and depression scores from the HADS
3. Physical status: Karnofsky performance status scale
3.9 Procedure

3.9.1 Identification of suitable patients

The researcher(s) would attend the pre-clinic meetings where the clinical staff would briefly discuss the patients due to attend the clinic. This provided the best opportunity for the clinicians to identify patients that in their opinion would be suitable for inclusion in the study.

When patients arrived in the clinic and settled themselves in the waiting room, the researcher would approach them and ask whether they minded if we took a few minutes of their time to talk to them about the research project. If they agreed we would provide them with a brief outline of the study. If they showed an interest at this stage we would ask them if they would like to read the study information sheet (see Appendix C: Information Sheets). At this point we would inform the patient that we would give them some time to read the information sheet and that we would return in a short while to see whether or not they might be interested in participating. The patients were also given the opportunity to ask any questions they might have regarding the study.

3.9.2 Informed consent

Participants were given sufficient time to read the information sheet for the study and to discuss with close persons before deciding whether to take part. Any decision not to take part in the study or not to talk to the researchers was respected and patients were reminded again at consent that the study was voluntary and they were free to withdraw at any time without needing to give a reason. A copy of the consent form was sent to each patient and another copy was placed in their notes. (See Appendix D: Consent Forms)

3.9.3 Completion of the questionnaires

If it was convenient for the patient they would be asked to complete the baseline questionnaires while in the clinic. If this was inconvenient we would make alternative arrangements, usually to visit them at home. Approximately six weeks after the baseline assessment we would contact the patient to arrange for the completion of the follow-up questionnaire at eight weeks. This assessment was usually conducted in their homes and occasionally on their next visit to the clinic, whichever was the most convenient for them.

3.9.4 Allocation to Groups

Preference intervention- Participants in this group chose to receive the advance care planning intervention.

Preference usual care- Participants in this group chose not to receive the advance care planning intervention and instead continued with usual care.

Randomisation- Participants in this group had a 50% chance of receiving the intervention and were happy to be randomised to either usual care or advance care planning discussion.

Preferences were collected on all participants. While the preference arms of the trial were open patients could choose to be in the intervention group, the usual care group or be randomised. Once the preference arms were closed all patients recruited were randomised regardless of any preference they may have expressed.
3.9.5 Randomisation process and blinding

Randomisation took place after patients gave consent to the study and the baseline measures had been completed. Randomisation was kept strictly separate from the research assessment and allocation. The trial statistician assembled a randomised sequence of allocations to each trial arm, constrained in blocks of between 4 and 6 in order to keep each trial arm of approximately the same size. The block size used at any one point was randomly selected. Once the assessment was completed the researcher rang into the trial centre to give the patients’ details to the independent mediator who then randomised them. Once the patient had been randomised the mediator would contact them to let them know which group they would enter, and where they had been randomised to the advance care planning intervention would arrange a time and place to carry out the discussion.

Both the statistician analysing the results and the two researchers were keep blind of randomised patients’ allocation. At baseline, patients entering the randomised arm were asked by the researcher not to reveal to them the group they were in when they completed the follow-up measures.

3.9.6 Data management

The study followed guidelines for data protection ensuring that all participant information was kept in a locked filing cabinet only identifiable by participant numbers. All databases containing participant information were password protected. Patient identities were only known to researchers within the team.

Letters were sent to GPs advising them of their patients’ participation in the trial following Good Clinical Practice (GCP) guidelines. This was particularly important due to the nature of the trial, where participants might refer to their GP for advice on advance directives or end-of-life concerns after taking part.

3.9.7 Data analysis

The number of participants for this feasibility trial was selected on a pragmatic basis to inform the sample size and statistical power required for a definitive Phase III RCT, therefore no formal power calculation was conducted. Descriptive statistics of all baseline measures were generated for all patients, stratified by whether patients chose their trial arm or were randomised and by intervention (usual care or advance care planning). The randomised arm was further stratified by whether or not the preference arm was open.

The visual analogue scales were grouped into three domains: (i) communication (ii) discussion about the future and (iii) satisfaction.

Domains (ii) and (iii) were each split into two further sub domains: communication/discussion with health care professionals and communication/discussion with friends and family.

The scores from the scales belonging to each grouping were summed to provide a summary score for analysis. To assess the internal consistency of each summary score, Cronbach’s alpha was calculated.

Analysis of Variance (ANOVA) models of each outcome measure at follow-up (HADS depression and anxiety scores, and visual analogue scale domain and sub domain summary scores) were fitted with the baseline score and treatment group as covariates. Further adjustment for possible confounding variables was investigated.
Logistic regression was used to model follow-up responses to questions involving yes or no answers, with the baseline response and treatment group as covariates.

Analyses were conducted separately for
(i) the randomised cohort (ii) the preference cohorts and (iii) both cohorts combined.

### 3.10 Intervention methods

#### 3.10.1 Advance care planning discussions

The intervention – the Advance Care Planning discussion - consisted of a one-to-one discussion with the trained care planning mediator using a checklist of topic domains, derived from Phase I work (Barnes et al 2007), and introduced as appropriate for each individual (see Appendix E: Advance Care Planning Discussion Schedule). All discussions were audio taped. The questions within each domain formed a guide for the care planning mediator and were used as prompts in the discussion. We aimed to explore patient’s perceptions of their current situation, how this was influenced by past care, and to address hopes and fears for the future. Through this structure the discussions aimed to cover the following domains:

<table>
<thead>
<tr>
<th>Main domains covered in ACP discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) General quality of care so far (to open up the discussion)</td>
</tr>
<tr>
<td>2) Feelings about the future</td>
</tr>
<tr>
<td>3) Discussing the future with doctors and nurses</td>
</tr>
<tr>
<td>4) Discussing the future with family and friends</td>
</tr>
<tr>
<td>5) Concerns regarding the future, including financial worries, preparation of a last will and most important areas of care when thinking about the future</td>
</tr>
<tr>
<td>6) Death and dying</td>
</tr>
<tr>
<td>7) Preferred place of care</td>
</tr>
<tr>
<td>8) Identifying coping mechanisms</td>
</tr>
<tr>
<td>9) Future health care decisions, including views on resuscitation and an option to complete an Advance Directive, Lasting Power of Attorney or Statement of wishes and Preferences (Terrence Higgins Trust documents were given to patients where appropriate).</td>
</tr>
<tr>
<td>10) Participants’ feelings at the end of the discussion and desire to complete another ACP discussion</td>
</tr>
</tbody>
</table>

The topic schedule was used as a guide to facilitate a structure for discussions. At all times the mediator aimed to be sensitive to verbal and non-verbal clues from participants as to how far to pursue each domain. In this way, we expected that there would be variation in the depth to which each domain was explored, according to participant need and acceptability of theme. Not every question was always asked, but discussions were tailored in response to the needs of the individual. Participants were also free to introduce other topics of importance to them.

The topic guide was piloted in role play sessions within the research team and with patients attending a hospice day therapy unit and adjustments made to its precise content and suggested wording for use by the mediator in introducing domains.
The intention was for participants to be seen alone at the first session but other family members could be present at subsequent sessions if participants requested. These additional interviewees also gave informed consent (see Appendix D: Consent forms).

When appropriate the mediator brought to attention of the participant the availability of documenting future healthcare decisions in the form of an advance directive. For those patients who wished to complete a written advance directive, Terrence Higgins Trust documents were used (Appendix B). In such cases, participants were asked to consider whether they would like to keep their advance directive themselves or to pass copies to their clinical team so that such documents would be kept in their medical records in which case advice was given on how this could be achieved.

3.10.2 The Advance Care Planning Mediator

Informed by the findings from Phase I the mediator was independent of the clinical team (Barnes et al., 2007). Since we were unsure of the likely nature and content of the discussions, for this research we chose mediators with significant clinical experience. The first mediator was a research nurse experienced in oncology and palliative care who had undertaken the DH advanced communications skills course. Half way through the study this nurse moved to another post. The second mediator was a palliative care physician experienced in the management of patients with advanced illness in particular in an outpatient setting. Both mediators engaged in extensive role play sessions with both male and female members of the research team before commencing their work. Both mediators did not divulge to study participants the nature of their professional backgrounds and at no time gave any clinical advice.

3.10.3 Procedure for the ACP discussion

The names and contact details of participants who were to be randomised or those who had a strong preference to receive the intervention were given to the care planning mediator. The participants in the randomisation arm were assigned to either the intervention or usual care group, determined by opening a sealed envelope for each participant.

The care planning mediator telephoned each participant to introduce herself, and for those in the randomisation arm, she informed them of which group they had been assigned to. She then arranged a convenient time for the first Advanced Care Planning (ACP) discussion. Participants were given a choice concerning where they would like to complete the discussion – in their own homes, at the Marie Curie Palliative Care Research Unit or at the local Marie Curie Hospice.

At the start of the discussion the care planning mediator informed participants that the purpose of the discussion was to talk together about the future - any concerns they may have and their preferences/wishes for future care. She acknowledged that participants may not have thought through these things before and may not know how they felt. She explained that she wasn’t there to give specific advice, but to encourage and help participants think through the issues raised.

The care planning mediator informed participants that the discussion would last up to one hour, but they could meet for another two sessions to discuss the issues further if necessary. If participants were unsure whether they wanted to meet again, the care planning mediator either arranged to contact them after one week or left her contact details with the participant. If, for some reason, it was not possible to complete all three discussions within the eight week study period and prior to the main study follow-up date, the final discussion was scheduled within a month of the study follow-up date.
The content of the second and third discussions focused on the main domains, but with a specific emphasis on those areas that were highlighted during the first discussion as possibly requiring some further dialogue.

The care planning mediator informed participants that relatives could not be present during the first discussion, but were welcome to attend subsequent discussions if the patient wanted them there. Where relatives were present, they were asked to sign a relatives’ consent form.

Part way through the study, the initial care planning mediator moved on from working with the unit and was replaced by another person. Prior to her departure, she spent time training the person who took her place to ensure consistency and to ensure that discussions were completed in the same manner by both care planning mediators.

3.10.4 Analysis of qualitative data

Tape recordings of the ACP discussions were transcribed verbatim. The transcripts were analysed using thematic content analysis to explore the content and context of discussions (Ritchie and Lewis). A manual method was used to study the transcripts and draw out the main themes under each of the topic domains.

A second researcher reviewed a random sample of 10% of the transcripts and any differences in interpretation were agreed by consensus. Emerging headings and themes were categorised and summarised under each topic domain and this document was then condensed and further summarised, re-categorising certain points as appropriate. The transcripts were continually reread throughout the process of analysis, to ensure that the emerging themes were firmly rooted in the original data and to identify quotations that encapsulated the meaning of these themes.
4 Results

Seventy eight patients were recruited into the study and 68 (88%) patients completed the trial to follow-up. Figure 4.1 shows the course of patients through the trial.

Figure 4.1 Enrolment and outcomes

<table>
<thead>
<tr>
<th>Approach (n=180)</th>
<th>Preference Arm Open</th>
<th>Preference Arm Closed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listened to study &amp; read information sheet (n=115)</td>
<td>Consented (n=55, 48%)</td>
<td>Refused (n=43)</td>
</tr>
<tr>
<td>Refused (n=60)</td>
<td>Preference (n=36)</td>
<td>Listened to study &amp; read information sheet (n=65)</td>
</tr>
<tr>
<td>Consented (n=22, 69%)</td>
<td>Usual care (n=15)</td>
<td></td>
</tr>
<tr>
<td>Intervention (n=21)</td>
<td>Lost to follow up (n=4)</td>
<td>Usual care (n=12)</td>
</tr>
<tr>
<td>Reason: too ill</td>
<td>Lost to follow up (n=2)</td>
<td>Lost to follow up (n=0)</td>
</tr>
<tr>
<td>Usual care (n=8)</td>
<td>Lost to follow up (n=0)</td>
<td></td>
</tr>
<tr>
<td>Completed study (n=31)</td>
<td>Usual care (n=10)</td>
<td>Lost to follow up (n=1)</td>
</tr>
<tr>
<td>Lost to follow up (n=1)</td>
<td>Usual care (n=11)</td>
<td>Reason: too ill</td>
</tr>
<tr>
<td>Completed study (n=16)</td>
<td>Usual care (n=8)</td>
<td></td>
</tr>
<tr>
<td>Completed study (n=47, 86%)</td>
<td>Preference Arm Open</td>
<td></td>
</tr>
<tr>
<td>Total completed study (n=68, 88%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.1 Response to recruitment

4.1.1 Attrition

During the course of the study nine participants were lost to follow-up with numbers varying between groups from four participants lost to follow up in the preference cohort usual care arm to no participants lost to follow up in the intervention arm (preference cohort closed). As shown in Table 4.1 below there were four main reasons patients were lost to follow-up: one died, three withdrew, two patients were un-contactable and three patients were too ill to continue. Two of the three patients who withdrew from the study gave no reason and one did so because they felt that the study was too morbid. Baseline data was not available for one of those patients lost to follow up in the preference usual care arm. One of the un-contactable patients had moved out the country and the other was not answering phone messages.
Table 4.1 Reason for attrition in each of the trial arms

<table>
<thead>
<tr>
<th>Reason for attrition</th>
<th>Preference ACP</th>
<th>Preference usual care</th>
<th>Randomised ACP (preference arms open)</th>
<th>Randomised usual care (preference arms open)</th>
<th>Randomised ACP (preference arms closed)</th>
<th>Randomised usual care (preference arms closed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too ill to continue</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Died</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Withdrew</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Un-contactable</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

4.1.2 Preferences

Thirty-eight participants (51%) recorded a preference for ACP, 26 (35%) no preference, and 11 (15%) a preference for usual care. The distribution of preferences was similar across most baseline demographic variables (Figure 4.2). The most notable differences were that more participants in the lower socio-economic groups and more school only qualified participants recorded a preference for usual care.

Figure 4.2 Medians and inter-quartile ranges (25th and 75th centiles) of preferences by baseline demographic variables.
4.1.3 Balance of Cohorts and Arms

Fifty-one percent of the 78 participants for whom baseline data were available were male, and 92% were of white ethnicity. The highest level of qualification completed was at university level for 20% of participants, and at post-graduate level for 42% of participants. Sixteen percent were from a low socio-economic group, and almost 59% were from a high socio-economic group. Thirty-six percent of participants stated they observed the Christian religion, 13% observed another religion, and 51% did not observe any religion. The median Karnofsky Performance Status Scale (KPSS) score was 100%.

Table 4.3 presents summary statistics of all baseline demographics. Means and standard deviations are given for continuous variables except where data were skewed, in which case the median and inter-quartile range (25th and 75th centiles) are given. For categorical variables, the number of patients in each category is provided along with the percentage of patients from the group in that category.

Preferences: Patients assigned to the randomised cohort had a median score of zero on the preference VAS in both the ACP and usual care arms, indicating that on average they did not have a preference for either treatment.

In the preference cohort, those patients who chose to be in the ACP group all had a preference for receiving ACP (median of 4). Patients who chose to be in the usual care group of the preference cohort mostly had a preference for receiving usual care (median of -4), though two patients scored zero (indicating no preference) and one patient scored 3 (indicating a preference for ACP).

Age: The distribution of ages was similar in the treatment arms of the randomised cohort, though there was a larger spread in the usual care arm. In the preference cohort, those who chose usual care tended to be older than those who chose ACP.

Socio-economic group: In the randomised cohort, the distribution of socio-economic group was similar across arms. In the preference cohort, patients who chose ACP tended to be in a high socio-economic group. All but one patient was in group three or above.

Education: In both the preference cohort and the randomised cohort, there were higher percentages of post-graduate qualified participants in the ACP groups, compared to the usual care groups.

Patient diagnosis: The most common diagnoses were bowel (15%), prostate (14%), and gynaecological (11%). The median number of years of illness was 2 years (Table 4.2).

Time ill: In the randomised cohort, patients in the usual care arm had on average been ill for longer (median 4 years) than patients randomised to ACP (median 2 years). In the preference cohort, the distribution of length of illness was similar across arms.
Table 4.2 Patients’ diagnoses and time ill by treatment group

<table>
<thead>
<tr>
<th>Diagnosis, n (%)</th>
<th>Preference Cohort</th>
<th>Randomised Cohort</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ACP (n=21)</td>
<td>Usual (n=14)</td>
<td>ACP (n=22)</td>
</tr>
<tr>
<td>lung</td>
<td>1 (4.8)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>prostate</td>
<td>2 (9.5)</td>
<td>1 (6.7)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>breast</td>
<td>1 (4.8)</td>
<td>0 (0.0)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>renal</td>
<td>0 (0.0)</td>
<td>2 (13.3)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>melanoma</td>
<td>0 (0.0)</td>
<td>2 (13.3)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>lymphoma</td>
<td>2 (9.5)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>neuro-endocrine</td>
<td>2 (9.4)</td>
<td>1 (6.7)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>brain</td>
<td>1 (4.8)</td>
<td>0 (0.0)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>bowel</td>
<td>4 (19.1)</td>
<td>3 (20.0)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>multiple sites</td>
<td>1 (4.8)</td>
<td>2 (13.3)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>other</td>
<td>2 (9.5)</td>
<td>2 (13.3)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>colorectal</td>
<td>2 (9.5)</td>
<td>2 (13.3)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>gynaecological</td>
<td>2 (9.5)</td>
<td>0 (0.0)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>pancreatic</td>
<td>0 (9.5)</td>
<td>0 (0.0)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>unknown</td>
<td>1 (4.8)</td>
<td>1 (6.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>time ill (years), median (IQR)</td>
<td>2 (1, 4)</td>
<td>1 (1, 2.3)</td>
<td>2 (1, 3.5)</td>
</tr>
</tbody>
</table>

All Other Variables: The distribution of all other baseline variables was similar across arms and cohorts.
Table 4.3 Summary statistics of the baseline data, by cohort and treatment group.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Preference Cohort</th>
<th>Randomised Cohort</th>
<th>Total (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ACP (n=21)</td>
<td>Usual (n=14)</td>
<td>ACP (n=22)</td>
</tr>
<tr>
<td>preference, median (IQR*)</td>
<td>4 (3.5, 5)</td>
<td>-4 (-5, -0.8)</td>
<td>0 (0, 4)</td>
</tr>
<tr>
<td>gender, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>10 (47.6)</td>
<td>7 (50.0)</td>
<td>12 (57.1)</td>
</tr>
<tr>
<td>female</td>
<td>11 (52.4)</td>
<td>7 (50.0)</td>
<td>9 (42.9)</td>
</tr>
<tr>
<td>age (years), mean (sd)</td>
<td>61.95 (11.03)</td>
<td>67.71 (7.89)</td>
<td>58.57 (8.11)</td>
</tr>
<tr>
<td>marital status, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>single, never married</td>
<td>4 (19.1)</td>
<td>0 (0.0)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>married</td>
<td>9 (42.9)</td>
<td>10 (71.4)</td>
<td>9 (42.9)</td>
</tr>
<tr>
<td>other</td>
<td>8 (38.1)</td>
<td>4 (28.6)</td>
<td>9 (42.9)</td>
</tr>
<tr>
<td>ethnicity, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>20 (95.2)</td>
<td>13 (92.8)</td>
<td>18 (85.7)</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1 (4.8)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0.0)</td>
<td>1 (7.1)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>employment, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>employed/self-employed</td>
<td>8 (38.1)</td>
<td>5 (35.7)</td>
<td>9 (42.9)</td>
</tr>
<tr>
<td>retired</td>
<td>11 (52.4)</td>
<td>7 (50.0)</td>
<td>8 (38.1)</td>
</tr>
<tr>
<td>other</td>
<td>2 (9.5)</td>
<td>2 (14.3)</td>
<td>4 (19.1)</td>
</tr>
<tr>
<td>socio-economic group, n (%)</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 (11.1)</td>
<td>2 (11.1)</td>
<td>1 (6.7)</td>
</tr>
<tr>
<td></td>
<td>1.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 (38.9)</td>
<td>2 (16.7)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1 (8.3)</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4 (22.2)</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>0 (0.0)</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>0 (0.0)</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>0 (0.0)</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>1 (5.6)</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td>education, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>school</td>
<td>6 (28.6)</td>
<td>8 (61.5)</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>university</td>
<td>3 (14.3)</td>
<td>2 (15.4)</td>
<td>5 (26.3)</td>
</tr>
<tr>
<td>post-graduate</td>
<td>12 (57.1)</td>
<td>3 (23.1)</td>
<td>11 (57.9)</td>
</tr>
<tr>
<td>religion, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>7 (33.3)</td>
<td>6 (42.9)</td>
<td>6 (28.6)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (23.8)</td>
<td>2 (14.3)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>None</td>
<td>9 (42.9)</td>
<td>6 (42.9)</td>
<td>13 (61.9)</td>
</tr>
<tr>
<td>KPSS, median (IQR)</td>
<td>100 (80, 100)</td>
<td>100 (90, 100)</td>
<td>100 (100, 100)</td>
</tr>
<tr>
<td>number of sessions, mean (sd)</td>
<td>1.19 (0.51)</td>
<td>NA</td>
<td>1.29 (0.64)</td>
</tr>
<tr>
<td>days to follow-up, median (IQR)</td>
<td>75 (63, 80.8)</td>
<td>78 (70, 92)</td>
<td>71 (64, 85)</td>
</tr>
</tbody>
</table>

* IQR=Inter-quartile range, the 25th and 75th centiles.
4.2 Quantitative Analysis

4.2.1 Visual Analogue Scale Domains

The visual analogue scales were grouped into three domains:

1. Communication – (Questions 1, 2, 5, 6, of the form, “I am happy with the level of communication I have with…”).

2. Discussion about the future – (Questions 7, 8, 9, 11, 12, of the form, “I have talked with… about the care I would prefer if I were to become very ill.”).

3. Satisfaction with health care – (Questions 17, 18, 19, 20, 21, of the form, “Overall have you felt satisfied with…”)

Domains (1) and (2) were each split into two further sub-domains: communication/discussion with health care professionals and communication/discussion with friends and family (The VAS can be found in appendix A).

The scores from the scales belonging to each grouping were summed to provide a summary score for analysis. To assess the internal consistency of each summary score, Cronbach’s alpha was calculated.

Cronbach’s alpha was greater than 0.6 for all VAS domains and sub-domains (Table 4.4), indicating satisfactory internal consistency reliability of the amalgamated VAS scales.

Table 4.4 Cronbach’s alpha of visual analogue scale domains and sub domains

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Professionals</th>
<th>Friends &amp; Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>0.67</td>
<td>0.77</td>
<td>0.63</td>
</tr>
<tr>
<td>Discussed the Future</td>
<td>0.80</td>
<td>0.78</td>
<td>0.83</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>0.87</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

4.2.2 Descriptive Statistics of the Measures

Table 4.5 provides the means and standard deviations of the communication, discussion and satisfaction VAS domain scores at baseline by cohort and arm.

Table 4.5 Means and standard deviations of VAS domain scores at baseline

<table>
<thead>
<tr>
<th></th>
<th>Randomised Cohort (n=42)</th>
<th>Preference Cohort (n=35)</th>
<th>Combined (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual Care</td>
<td>ACP</td>
<td>Usual Care</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overall</td>
<td>34.9 (5.2)</td>
<td>34.3 (4.4)</td>
<td>37.6 (2.6)</td>
</tr>
<tr>
<td>with professionals</td>
<td>17.6 (2.7)</td>
<td>16.9 (2.8)</td>
<td>18.5 (2.0)</td>
</tr>
<tr>
<td>with family &amp; friends</td>
<td>17.6 (3.4)</td>
<td>17.4 (2.4)</td>
<td>19.1 (1.5)</td>
</tr>
<tr>
<td>Discussion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overall</td>
<td>8.4 (9.6)</td>
<td>7.8 (11.9)</td>
<td>6.8 (10.4)</td>
</tr>
<tr>
<td>with professionals</td>
<td>3.0 (4.8)</td>
<td>2.9 (7.4)</td>
<td>1.9 (5.3)</td>
</tr>
<tr>
<td>with family &amp; friends</td>
<td>5.4 (6.3)</td>
<td>4.9 (7.2)</td>
<td>4.9 (6.9)</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overall</td>
<td>42.2 (6.2)</td>
<td>39.6 (8.1)</td>
<td>46.2 (4.2)</td>
</tr>
</tbody>
</table>
Table 4.6 provides the means and standard deviations of the communication, discussion and satisfaction VAS domain scores at follow-up by cohort and arm.

Table 4.6 Means and standard deviations of VAS domain scores at follow-up

<table>
<thead>
<tr>
<th></th>
<th>Randomised Cohort (n=42)</th>
<th>Preference Cohort (n=35)</th>
<th>Combined (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual Care</td>
<td>ACP</td>
<td>Usual Care</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overall</td>
<td>33.9 (6.0)</td>
<td>31.6 (7.3)</td>
<td>37.1 (2.7)</td>
</tr>
<tr>
<td>with professionals</td>
<td>17.1 (2.8)</td>
<td>15.9 (3.7)</td>
<td>18.4 (1.9)</td>
</tr>
<tr>
<td>with family &amp; friends</td>
<td>16.8 (4.0)</td>
<td>15.8 (4.6)</td>
<td>18.4 (2.5)</td>
</tr>
<tr>
<td>Discussion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overall</td>
<td>11.4 (15.0)</td>
<td>11.8 (13.0)</td>
<td>8.3 (9.4)</td>
</tr>
<tr>
<td>with professionals</td>
<td>5.3 (9.3)</td>
<td>5.0 (8.1)</td>
<td>2.3 (3.9)</td>
</tr>
<tr>
<td>with family &amp; friends</td>
<td>6.1 (6.9)</td>
<td>6.6 (6.0)</td>
<td>6.0 (6.5)</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overall</td>
<td>44.3 (4.6)</td>
<td>40.2 (8.6)</td>
<td>45.6 (5.9)</td>
</tr>
</tbody>
</table>

Table 4.7 provides the means and standard deviations of the HADs anxiety and depression scores at baseline by cohort and arm

Table 4.7 Means and standard deviations of HADs scores at baseline

<table>
<thead>
<tr>
<th></th>
<th>Randomised Cohort (n=42)</th>
<th>Preference Cohort (n=35)</th>
<th>Combined (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual Care</td>
<td>ACP</td>
<td>Usual Care</td>
</tr>
<tr>
<td>HADs Anxiety</td>
<td>7.1 (4.6)</td>
<td>6.2 (4.7)</td>
<td>4.4 (3.3)</td>
</tr>
<tr>
<td>HADs Depression</td>
<td>4.0 (2.6)</td>
<td>5.5 (2.9)</td>
<td>3.4 (2.6)</td>
</tr>
</tbody>
</table>

Table 4.8 provides the means and standard deviations of the HADs anxiety and depression scores at follow-up by cohort and arm

Table 4.8 Means and standard deviations of HADs scores at follow-up

<table>
<thead>
<tr>
<th></th>
<th>Randomised Cohort (n=42)</th>
<th>Preference Cohort (n=35)</th>
<th>Combined (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual Care</td>
<td>ACP</td>
<td>Usual Care</td>
</tr>
<tr>
<td>HADs Anxiety</td>
<td>7.1 (3.6)</td>
<td>6.6 (5.0)</td>
<td>4.7 (3.0)</td>
</tr>
<tr>
<td>HADs Depression</td>
<td>4.9 (2.6)</td>
<td>5.2 (3.4)</td>
<td>3.4 (1.9)</td>
</tr>
</tbody>
</table>

4.2.3 Analyses of the communication, discussion and satisfaction visual analogue scales

The analyses report a comparison between the ACP and usual care arms within each cohort, where usual care is the baseline treatment group. Analysis of Covariance (ANCOVA)
was used for this analysis as it adjusts each patient’s follow-up score for their baseline score and provides a precise and unbiased estimate of treatment effects. The treatment coefficient is the effect of interest as it is the estimated difference between treatment groups. A positive coefficient indicates the domain score was higher on average in the ACP arm and a negative coefficient indicates the domain score was higher on average in the usual care arm. In effect the ANCOVA adjusts each patient’s follow up score for their baseline score. This method has the advantage of being unaffected by baseline differences. The confidence intervals are wide due to the small numbers included in this feasibility trial.

**Table 4.9** Treatment coefficients of ANCOVA models of VAS domains adjusting for baseline score and cohort (in the combined models), with 95% confidence intervals and p-values.

<table>
<thead>
<tr>
<th></th>
<th>Randomised Cohort (n=42)</th>
<th>Preference Cohort (n=35)</th>
<th>Combined (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coef.</td>
<td>95% CI</td>
<td>p-value</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>with professionals</td>
<td>treatment</td>
<td>0.31</td>
<td>(-4.52, 5.14)</td>
</tr>
<tr>
<td></td>
<td>with family/friends</td>
<td>-0.30</td>
<td>(-3.18, 2.59)</td>
</tr>
<tr>
<td>Discussion</td>
<td>treatment</td>
<td>1.27</td>
<td>(-6.40, 8.95)</td>
</tr>
<tr>
<td></td>
<td>with professionals</td>
<td>-0.02</td>
<td>(-5.16, 5.12)</td>
</tr>
<tr>
<td></td>
<td>with family/friends</td>
<td>1.16</td>
<td>(-2.16, 4.49)</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>treatment</td>
<td>-2.04</td>
<td>(-5.77, 1.69)</td>
</tr>
</tbody>
</table>

**4.2.3.1 Communication Overall**

There were no statistically significant differences in patients communication overall, with health care professionals or with friends/family in the randomised, preference or combined cohorts at the 5% level (Table 4.9).

In the preference cohort, happiness with level of communication patients reported having experienced overall tended to be higher in the usual care arm. On average, the total communication score was 1.47 units (increments on the visual analogue scale) lower in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score (with 95% confidence interval from -4.74 to 1.81).

**4.2.3.2 Communication with Professionals**

There were no statistically significant differences in patients’ happiness with levels of communication with health care professionals in the randomised, preference or combined cohorts at the 5% level.
In the preference cohort, happiness with level of communication patients had with professionals tended to be higher in the usual care arm. On average, the communication with professionals score was 1.81 units lower in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score (with 95% confidence interval from -3.90 to 0.28).

4.2.3.3 Communication with Friends and Family

There were no statistically significant differences in patients’ happiness with levels of communication with friends/family in the randomised, preference or combined cohorts at the 5% level.

4.2.3.4 Discussion Overall

There were no statistically significant differences in discussion with anyone about preferred future care in the randomised, preference or combined cohorts at the 5% level.

In the randomised cohort, discussion with anyone about preferred future care tended to be higher in the ACP arm. On average, the discussion with anyone score was 1.27 units higher in patients assigned to ACP compared with patients assigned to usual care in the randomised cohort, adjusting for baseline score (with 95% confidence interval from -6.40 to 8.95).

In the preference cohort, discussion with anyone about preferred future care tended to be higher in the ACP arm. On average, the discussion with anyone score was 2.19 units higher in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score (with 95% confidence interval from -4.73 to 9.11).

Discussion with anyone about preferred future care also tended to be higher in the ACP arm when the cohorts were combined. On average, the discussion with anyone score was 1.26 units higher in patients assigned to ACP compared with patients assigned to usual care in the combined cohorts, adjusting for baseline score and cohort (with 95% confidence interval from -4.10 to 6.62).

4.2.3.5 Discussion with Professionals

There were no statistically significant differences in discussion with health care professionals about preferred future care in the randomised, preference or combined cohorts at the 5% level.

Randomised cohort: There was no difference in discussion with professionals about preferred future care between the usual care and ACP arms in the randomised cohort. In the preference cohort, discussion with professionals about preferred future care tended to be higher in the ACP arm. On average, the discussion with professionals score was 2.94 units higher in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score (with 95% confidence interval from -0.95 to 6.84).

4.2.3.6 Discussion with Friends and Family

There were no statistically significant differences in discussion with friends/family about preferred future care in the randomised, preference or combined cohorts at the 5% level.
In the randomised cohort, discussion with friends and family about preferred future care tended to be higher in the ACP arm. On average, the discussion with friends and family score was 1.16 units higher in patients assigned to ACP compared with patients assigned to usual care in the randomised cohort, adjusting for baseline score (with 95% confidence interval from -1.91 to 3.22). Preference cohort: There was no difference in discussion with friends and family about preferred future care between the usual care and ACP arms in the preference cohort.

Preference cohort: There was no difference in discussion with friends and family about preferred future care between the usual care and ACP arms when the cohorts were combined.

4.2.3.7 Satisfaction with support and communication overall

There were no statistically significant differences in patient satisfaction with communication in the randomised, preference or combined cohorts at the 5% level.

In the randomised cohort, satisfaction tended to be higher in the usual care arm. On average, the satisfaction score was 2.04 units lower in patients assigned to ACP compared with patients assigned to usual care in the randomised cohort, adjusting for baseline score (with 95% confidence interval from -5.77 to 1.69).

In the preference cohort, satisfaction tended to be higher in the usual care arm. On average, the satisfaction score was 4.86 units lower in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score (with 95% confidence interval from -12.31 to 2.59).

Satisfaction tended to be higher in the usual care arm when the cohorts were combined. On average, the satisfaction scores was 3.05 units lower in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score and cohort (with 95% confidence interval from -6.55 to 0.45).

4.2.3.8 Covariates

All models were additionally fitted with four covariates: age, gender (with male as the baseline), time ill and preference (as measured by the VAS). Results are only presented where there was a trend or pattern in the effect of the covariates to avoid highlighting spurious effects. Some results were statistically significant but there was no pattern in the significance suggesting they were probably chance results.

Preference Cohort, Discussion overall: In the preference cohort the estimated effect of treatment was reversed when covariates were accounted for indicating less rather than more discussion in the ACP arm. Neither age nor gender had a large estimated effect in the adjusted model. The result for length of time ill indicated more discussion took place the longer the participant had been ill and that the result for preference score indicated that there was more discussion where the participant’s preference was towards receiving ACP.

Preference Cohort, Discussion with professionals: A similar reversal of treatment effect was observed in the adjusted model for discussion with professionals, whereby the adjusted model indicated less discussion in the ACP arm. Neither age nor preference score had a large effect in the adjusted model, indicating less discussion with professionals in females than males. The results indicated more discussion took place with professionals the longer a participant had been ill.
Preference Cohort, Discussion with Friends and Family VAS: The treatment effect for discussion with family and friends was stronger in the adjusted model. The result for preference score indicated that more discussion the more a participant’s preference was towards receiving ACP. None of the other covariates had a large estimate effect.

Preference Cohort, Satisfaction overall: The estimated effect of treatment was reversed in the adjusted model for satisfaction indicating higher satisfaction in the ACP arm. Neither age nor time ill had a large estimated effect in the adjusted model. Neither age nor time ill had a large estimated effect in the adjusted model. The result coefficient for gender indicated higher satisfaction in females than males. The result for preference score indicated lower satisfaction the more a participant’s preference was towards receiving ACP.

Randomised Cohort, Discussion: Although there were only minimal effects on the treatment coefficients of the adjusted models for the discussion VASs, there was a large estimated effect of gender in each adjusted model for the discussion VASs, indicating less discussion in females than males. This was the case for discussion with anyone, professionals and with family/friends.

4.2.4 Analyses of Anxiety and Depression

ANCOVA was used to analyse the anxiety and depressions domains of the HADs separately for each cohort (randomised and preference), and for the two cohorts combined. Baseline treatment is usual care, being compared with Advance Care Planning. Only the combined analysis adjusts for cohort, with randomised cohort as the baseline.

4.2.4.1 Anxiety

There were no statistically significant differences in anxiety between the usual care and ACP arms in the randomised cohort in either the randomised or preference cohorts, or when the cohorts were combined (Table 4.10).

4.2.4.2 Depression

There were no statistically significant differences in depression between the usual care and ACP arms in the randomised cohort in either the randomised or preference cohorts, or when the cohorts were combined.

In the randomised cohort, depression was slightly higher in the usual care arm. On average, the depression score was 0.89 units lower in patients assigned to ACP compared with patients assigned to usual care in the randomised cohort, adjusting for baseline score.

In the preference cohort, depression tended to be higher in the ACP arm. On average, the depression score was 1.18 units higher in patients assigned to ACP compared with patients assigned to usual care in the preference cohort, adjusting for baseline score.

There was no difference in depression score when the cohorts were combined.
Table 4.10  Treatment coefficients of ANCOVA models of HADs scores adjusting for baseline score and cohort (in the combined models), with 95% confidence intervals and p-values.

<table>
<thead>
<tr>
<th></th>
<th>Randomised Cohort (n=4)</th>
<th>Preference Cohort (n=35)</th>
<th>Combined (n=77)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coef.</td>
<td>95% CI</td>
<td>p-value</td>
</tr>
<tr>
<td>HADs Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>treatment</td>
<td>0.33</td>
<td>(-1.33, 1.99)</td>
<td>0.686</td>
</tr>
<tr>
<td>HADs Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>treatment</td>
<td>-0.89</td>
<td>(-2.52, 0.75)</td>
<td>0.281</td>
</tr>
</tbody>
</table>

4.2.4.3 Covariates

All models were additionally fitted with four covariates: age, gender (with male as the baseline), time ill and preference (as measured by the VAS). Results are only presented where there was a trend or pattern in the effect of the covariates to avoid highlighting spurious effects. Some results were statistically significant but there was no pattern in the significance suggesting they were probably chance results.

Preference Cohort, Depression: In the preference cohort the estimated effect of treatment was reversed in the adjusted model for HADs depression indicating lower depression scores in the ACP arm. The results also indicated higher depression scores in females. None of the other covariates had a large estimate effect.

4.2.5 Analyses of Multiple Choice Questions

4.2.5.1 Talked to Other Health Professionals

The question, “Are there other health professionals who you have talked with about the care you would prefer if you were to become very ill?” was asked at baseline and follow-up, with “no” and “yes” as possible answers. Logistic regression was used for this analysis as this is appropriate for questions where the response is dichotomous as it is here with “no” or “yes” answers. Table 4.11 presents the odds ratios and 95% confidence intervals from the logistic regression models of the effect of treatment on this question, adjusting for baseline score, and where the baseline treatment group is usual care.

Table 4.11  Treatment coefficient of logistic regression model

<table>
<thead>
<tr>
<th></th>
<th>Randomised Arm</th>
<th>Preference Arm</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR 95% CI p-value</td>
<td>OR 95% CI p-value</td>
<td>OR 95% CI p-value</td>
</tr>
<tr>
<td>treatment</td>
<td>9.00 (0.54, 150.56) 0.126</td>
<td>not possible to estimate*</td>
<td>11.66 (0.86, 158.23) 0.065</td>
</tr>
</tbody>
</table>

* not possible to estimate because all patients in the usual care arm responded 'no' to the question at both baseline and follow-up.

Randomised cohort: In the randomised cohort, participants in the ACP group were more likely to have talked with another health professional about the care they would prefer if they were to become very ill. The odds of there being other health professionals with whom
participants had talked about preferred care in the ACP group were estimated to be 9.00 times the odds in the usual care group, in the randomised cohort adjusting for baseline score.

**Preference cohort:** In the preference cohort, it was not possible to estimate the treatment effect because all patients in the usual care arm responded ‘no’ to the question at both baseline and follow-up.

**Combined cohorts:** Participants in the ACP group were more likely to have talked with another health professional about the care they would prefer if they were to become ill when the cohorts were combined. The odds of there being other health professionals with whom participants had talked about preferred care in the ACP group were estimated to be 11.66 times the odds in the usual care group, when the cohorts were combined, adjusting for baseline score and cohort.

### 4.2.5.2 Intention to Complete an Advance Directive

A further multiple choice question was not possible to analyse using logistic regression due to the pattern of responses. The question was, “I intend to complete an advance directive/living will”, and the possible answers were ‘yes’, ‘no’, ‘unsure’, and ‘have already completed one.’

The initial plan was to combine the first three groups and compare them using a logistic regression model with the ‘have already completed’ group, since it was of interest to see if treatment group had any effect on whether patients completed an advance directive or not. However, no patients who answered ‘have already completed’ at baseline also answered ‘have already completed’ at follow-up making this analysis impossible.

Four patients reported having already completed an advance directive at baseline, and three different patients reported having already completed an advance directive at follow-up. Table 4.12 summarises the responses of these patients, including their responses to the following two VAS questions: 1) “Prior to taking part in this study, I had heard of advance directives or living wills”, and 2) “Prior to taking part in this study, I was aware what an advance directive or living will is”. A score of 10 indicates very strong agreement with the statement, and a score of 0 indicates very strong disagreement with the statement. Three of the four patients who reported having already completed an advance directive at baseline changed their responses to the second of these questions from strong agreement to a lower score.

**Table 4.12:** Summary of patients who responded ‘have already completed’ to the question, “I intend to complete an advance directive/living will”, including patient ID (ID), cohort and arm assignment (group), answer to the question at baseline and follow-up, and answers to the VAS statements on having heard of an advance directive and being aware of what it is.

<table>
<thead>
<tr>
<th>ID</th>
<th>group</th>
<th>intend to completed AD</th>
<th>heard of AD</th>
<th>aware of what an AD is</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>baseline</td>
<td>follow-up</td>
<td>baseline</td>
</tr>
<tr>
<td>7</td>
<td>preference usual care</td>
<td>completed</td>
<td>no</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>preference ACP</td>
<td>completed</td>
<td>yes</td>
<td>9</td>
</tr>
<tr>
<td>16</td>
<td>randomised ACP</td>
<td>completed</td>
<td>yes</td>
<td>6</td>
</tr>
<tr>
<td>76</td>
<td>randomised ACP</td>
<td>completed</td>
<td>yes</td>
<td>9</td>
</tr>
<tr>
<td>21</td>
<td>preference usual care</td>
<td>unsure</td>
<td>completed</td>
<td>0</td>
</tr>
<tr>
<td>41</td>
<td>randomised ACP</td>
<td>no</td>
<td>completed</td>
<td>0</td>
</tr>
<tr>
<td>45</td>
<td>randomised ACP</td>
<td>unsure</td>
<td>completed</td>
<td>9</td>
</tr>
</tbody>
</table>
4.2.6 Summary of results

The study design allowed for the inclusion of small numbers as is usual in a feasibility trial and results should be interpreted with caution. No statistically significant results were found and confidence intervals were wide. No important statistical trends were observed. The trial arms were well balanced. A small number of participants from lower socio-economic groups and educated to school level only showed preferences for usual care. Levels of communication with health care professionals, satisfaction with support and overall communication were higher in those receiving usual care. Discussion about future care occurred more frequently in those receiving the ACP intervention and increased with duration of illness and was more common amongst men than women. No important effects on anxiety or depression were seen.
5. Results: Qualitative data

5.1 Advance care planning discussion schedule

Table 5.1 collection and analyses, including demographic table and information on numbers of subsequent discussions taking place

<table>
<thead>
<tr>
<th>Sample</th>
<th>N= 40 patients completed one or more ACP discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>19 female (47%) and 21 male (53%)</td>
</tr>
<tr>
<td>Number of ACP discussions completed</td>
<td>29 patients (73%) completed one discussion; 10 patients (25%) completed only two discussions; 1 patient (2%) completed three discussions</td>
</tr>
<tr>
<td>Relative(s) present during ACP discussion</td>
<td>5 patients (10%) had a relative(s) present during one of the discussions; 1 patient (3%) had a relative present during discussion 1; 4 patients (10%) during discussion 2 and 1 patient (3%) during discussion 3.</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>36 White (90%) 1 Black Caribbean (2.5%) 3 Other (7.5%)</td>
</tr>
<tr>
<td>Median age</td>
<td>60.8 years</td>
</tr>
<tr>
<td>Age range</td>
<td>42-78</td>
</tr>
</tbody>
</table>

Forty oncology patients completed at least one ACP discussion. Twenty nine patients (73%) completed one discussion; ten patients (25%) completed just two discussions and one patient (2%) completed all three discussions. In total, fifty two ACP discussions were analysed.

Five patients (13%) had a relative or relatives present during at least one of their ACP discussions. Four patients (10%) had a relative(s) present during the second discussion and one of these also had her relative present at the third discussion. In one instance, a family member appeared during the course of the first discussion and the care planning mediator didn’t feel it was appropriate to ask her to leave the room. (See Appendix F: Views of the care planning mediator on relatives being present during the discussion).

The length of discussions varied from approximately twenty-five minutes to an hour and fifty minutes. A small number of participants became emotional during the discussion, but none became unduly distressed or requested the discussion be discontinued. Where it was apparent during the course of the discussion that patients needed additional support or advice, the care planning mediator either encouraged them to make contact with their clinical team or gave them the Macmillan helpline.

MAIN THEMES ARISING

The main themes arising from the transcripts were categorized into ten categories: feelings about the future, communication with health professionals, communication with close persons, finances, death and dying, preferred place of care, identifying coping mechanisms, future health care decisions and general views expressed at the end of the discussion. (See Appendix G: Summary of main themes from ACP discussions).
5.1.1 Feelings about the future

i) Focusing on the positive and taking it one day at a time
When asked how they felt about the future, twenty-eight patients said that they had thoughts in the back of their minds about a possible deterioration in health but they were trying not to think about this, and were focusing on staying positive.

“You have got to be positive as well, so I don’t sort of dwell on it. I probably did when it was first confirmed that I had cancer, that’s when your mind’s racing and fears for the future, future of the family. But when things start getting a bit better with treatment, you push them aside and start thinking positively with things you want to do.” M60, session 1

Approximately half of those patients who completed the discussion said that they were taking it one day at a time, enjoying each day as it comes and not thinking too far ahead. Eight patients said they believed their attitude affected their health and that if they started thinking negatively, it would cause a deterioration in their health.

“In my more maudlin moments….I sit there and go through my funeral…. I also know that if I dwell on it, I’ll go right down and….I don’t want to do that. I have to live from day-to-day, and I have to find a way of managing it.” M16, session 1

“I’m quite positive about it… You don’t want to think in a negative way….you don’t want to be talking about things like that….because that makes you worse than what you are.” M49, session 1

There was a feeling amongst a number of patients that they didn’t know how to balance planning for their deterioration with maintaining a positive spirit.

“Acknowledging some of the realities…without sort of, uh, surrendering to them….is part of the problem.” M39, session 2

ii) Getting on with life as normal and making plans
Just under half of those patients who completed the discussion were attempting to remain positive by getting on with life as normal.

“I just think positive…..don’t give it a thought, I just want to get on with life.” M57, session 1

“It’s simply that I need to….continue with a life as well as we can, as normally as we can, for as long as we can.” M26, session 1

A third of patients said that they were making plans for enjoying the rest of their life and doing the things that they wanted to do. A smaller number said that they were not making as many long term plans and six patients said that not knowing how they would be feeling limited their ability to make long term plans.

“You can’t have long term plans. You can’t think of next year… I never think of next year now. I think of now.” M23, session 1

iii) Hope
Fifteen patients said that they had hope for the future and seven patients said that they were hopeful about the treatment options available to them. Six patients said that they were keeping positive by focusing on treatment options that might prolong their life expectancy.
“It’s this notion of realistic hope, isn’t it? I mean, I’m not stupid, I know that my life is going to be shortened, but I also know that people in my position can go on for years.” M16, session 1

“I’m just concentrating...on taking the...treatment medication.... keeping myself positive really....that’s my way of doing it. I do believe in mind over matter to a fair extent.” M32, session 1

**iv) Specific concerns about the future**

The care planning mediator asked patients if they had specific concerns regarding the future. Sixteen patients expressed some concern about the process of deterioration and the symptoms they might experience. Over half of these were concerned specifically about pain and being given sufficient analgesia.

“If it got worse, what’s my main fear? Pain. I’m a chicken.” M60, session 1

Fifteen patients said that they had fears or concerns regarding death or dying. Eight patients had had negative experiences seeing other people dying that had affected their attitude towards their own death.

Another common concern regarding the future was for family members, with just under half of the patients stating that their main concern when thinking about the future was for members of their family. Five patients expressed concerns about becoming physically dependent on others as they deteriorate and being a burden on those around them. Just under a third of patients said they were concerned about how their family would cope.

“They’re the ones I worry about, how they’ll cope.” M52, session 1

Eight patients said that they found the uncertainty regarding the future hard to deal with.

**5.1.2. Communication with health professionals**

Nearly all of the patients who completed the discussion indicated that they had not spoken extensively to their doctors about the future or what might happen when their health deteriorates. There appeared to be a number of reasons for this.

**i) Patients’ desire to talk about a future deterioration in health**

Sixteen said that they didn’t want to talk to their doctors about the future. About a third of patients felt it was too soon to have that kind of conversation, but also recognised that there may be a time to talk more extensively with their doctors.

“One knows the support is there so that when...one feels the time’s right to ask particular questions, you know the answers will be there....which is very reassuring.” M26, session 1

“If for instance Dr Davis said to me, ‘Look, it’s, it’s flaring up again’.... And if it was, then I think I’d say, ‘Well now, let’s plan.’” M23, session 1

A number of patients said that they didn’t want to think too far ahead and that receiving too much information about the future at one time would overload them.
Over half of the patients said that they wanted more information from their doctors about the future – what they can realistically expect, what the likely process of deterioration may look like and what their likely prognosis is. Just over a quarter of patients said that they wanted information from the doctors about the future whilst they still had time to plan.

“Hopefully they can manage to give me answers....Saying, ‘That’s what you have and that’s what you can do about it, or that’s what you can’t do about it’. That would be more important than just letting me....just carry on like this.” M9, session 2

Five patients suggested that there should be a specific person responsible for giving information to patients at each clinic visit – a contact point.

“I think at times it would be nice having a link person ....because I think you tend to get lost up there.” M45, session 1

ii) Health professionals’ desire to talk about a future deterioration in health

Over one third of patients said that their doctors were reluctant to give them information regarding the future.

“They always try to be positive.... He’s always trying to be upbeat, the consultant. So he’s not going to stop me to say, ‘What happens if it goes wrong?’ He doesn’t want to discuss it.” M33, session 1

“I’ve not enquired about that [preferred place of care], because as nice as people are, a lot of them would say ‘well wait till it happens’...So even the professionals, you know, there’s quite a few people who say, you know, ‘you’re alright at the moment, why don’t you wait till it happens’.” M10, session 2

Six patients said that they would take the lead from their health professionals on when to have conversations about the future. They recognised that they may need prompting in order to address certain issues, as they didn’t know what to ask for.

“There also needs to be a kind of a gentle nudging.... People...in my position, need the help.... Support.... needs to be there....so that....not only can you ask but you’re, I don’t know, prompted in a good way.” M26, session 1

“The biggest problem about getting care is knowing the right questions to ask.... If I’d known, if I’d thought to ask....I could have asked, but I didn’t know to ask.....That’s what I think you need as a patient .... I need gratuitous information.” M43, session 1

iii) Lack of time in clinic appointments

A third of patients brought up the issue of how much time is available in the clinic appointment, and said that the lack of time was one reason they haven’t felt able to talk with their doctors about the future. When talking about what might happen as his condition deteriorates, one patient said,

“The doctors, to be fair, are very busy, so I don’t really want to take up too much of their time, so I have not talked to them because it is probably quite a lengthy subject.” M60, session 1

“They are so busy, they never have to time to sit and talk about those things (the future) with you.” M9, session 1
5.1.3 Communication with close persons

Most of the patients said that they had talked with members of their family about their illness and treatment, but the extent to which patients had discussed the future with family members varied. Only a small number of patients appeared to have talked openly about the future with those closest to them. Twenty three patients said that they had only talked with those closest to them about specific things to do with the future, but certain issues had not yet been broached. Four patients said that they hadn’t discussed the future at all with those closest to them.

i) There is a time to talk to close persons about the future
Over half of the patients said that they didn’t want to talk to their family about the future at the moment. Eighteen patients said that they felt the time was not yet right for this discussion and ten patients said that they would talk more about these things if their condition deteriorated.

“I think timing is very important…. I don’t think you want, um, people to…become distressed too, too early….So it would be something that would be done in stages really.” M26, session 1

ii) Concern over how close persons would react
Eight patients expressed concern over how those close to them might react if they started talking to them about the future and nine patients said that they didn’t want to burden or upset them.

“It’s trying to find the balance….You have to try and plan for the worst case without unnecessarily upsetting or disturbing uh, those who are dependent on you…It’s…giving them and yourself you know, hope…by sort of, carrying on….as if there isn’t any real problem….But at the same time … adding the plans so that ….they are well catered for.” M39, session 1

iii) Desire to stay focused on the positive
Six patients (15%) said they felt it would be too negative to start talking to those close to them about the future and two patients (5%) said they feared it would bring on their deterioration if they started talking about these things.

“No, I haven’t talked about things like that with anyone….You don’t want to think in a negative way…. If I say to them ‘oh, I could be dead in 3 years’ they’d be saying…’ohhh’…You don’t want to be talking about things like that…..because that makes you worse than what you are.” M49, session 1

iv) Communication difficulties with family members
Fifteen patients identified some communication difficulties with family members concerning their illness and eight patients said that their relatives did not want to talk about their illness or the future. Six patients said that one or more of their family members were in denial about their illness.

“My partner….is very much in denial, you know. She doesn’t want to confront you know, the likelihood that I’ve uh, I’ve probably only got 2 or 3 years…Trying to persuade her to make the necessary adjustments in time….and help her do those.” M39, session 1
Four patients decided during the discussion to get additional help with communication difficulties within the family and nine patients realised that they wanted to talk to family members about the future after the discussion.

5.1.4 Finances

When asked about financial concerns, a small number said they had some financial worries, but approximately half of the patients had no financial concerns. Eight patients said that they had recently been doing some kind of financial planning for the future. Just under half of the patients had made a will and seven patients said they had plans to make a will or make changes to a current will.

Five patients said they had plans to talk to someone about benefits and the care planning mediator gave a small number of patients' details of the Macmillan benefits line to access further information concerning their benefit entitlement.

5.1.5 Death and dying

When asked if they had thought about dying, seventeen patients said that they had had some thoughts about death and six patients talked about death becoming a closer reality.

“Statistically I’m more likely to die than other people I know. But actually.....the reality is that we are all going to die....I think the difficult thing...with cancer is that you’re living with it, I’m living with it as a much closer reality.” M28, session 1

Just under half of the patients said that they did not want to think about death and dying and ten patients said that once they start to deteriorate, it will feel more appropriate to think and talk about this particular issue.

Only four patients said they had talked to their health professionals about the dying process and only four patients wanted to talk to the health professionals about this subject.

“I think it...I understood what uh, [may] possibly happen to me [regarding the dying process].....I think I would cope with it ok, but....I don’t know whether I’m ready to want to understand that at this present moment.” M26, session 1

5.1.6 Preferred Place of Care

i) Lack of knowledge on the options available

After the care planning mediator explained the options available to patients so that they could be cared for in a place of their choice, over half of the patients said that they hadn’t realised the options that were available to them and over one third of patients indicated that they found this information very helpful.

“It’s been very useful...to hear about Macmillan and Marie Curie and the local hospice, and actually feel, ‘well, that’s something that I can investigate at some point’.... It’s not easy to talk about these things at all, but...all information is power.” M40, session 1
ii) Preferred Place of Care would be at home
Twenty eight patients said that they would prefer to be cared for at home for as long as possible. Having control over their environment and maintaining some quality of life were given as reasons for this.

“I think if I had a choice I would rather be at home. Yes, I think just to have your things around you and be in a familiar place and somewhere that your family are used to coming to.” M52, session 1

However, for approximately half of the patients, concerns about being a burden on family or friends appeared to influence their choice for their preferred place of care and a third of patients expressed concern about placing a burden on those closest to them by being cared for at home. For some, this was indicative of a lack of knowledge about the level of support that is available to enable patients to stay at home.

“I think being cared for at home in the beginning is a good thing, but you put lots of pressure on people if you do that. So I probably would like to be at home for as long as I could.” M15, session 1

“I’d prefer to be in my own home....But if, if I did become a burden...if it was a burden on my wife, I would expect to be put into a home.” M29, session 1

iii) Does not want to think about preferred place of care at the moment
Six patients said that they didn’t want to think about their preferred place of care at the moment and eight patients said that their preferences would depend on their circumstances at the time.

“I will think about that...when the circumstances arise... If you don’t mind me saying so, the questions really are very premature right this very minute...there’s a long way to go yet in this life.” M4, session 2

5.1.7 Identifying coping mechanisms

When asked how they usually cope with difficult situations, twenty six patients said that having the right mental attitude was an important element in enabling them to cope with their current situation. Approximately half of the patients said that they found it helpful to talk to people and ten patients said that they found it helpful to talk with other cancer patients or those in a similar situation.

Twenty patients identified friends and family as a big source of support. A third of patients said that getting outdoors or getting physical exercise helped them and eleven patients talked about different forms of complementary therapies that they said were effective in enabling them to cope.

5.1.8 Future health care decisions

i) Trusting the medical profession to make decisions
Twenty six patients said that they would trust their nurses and doctors to make the best decisions on their behalf if they were unable to make those decisions themselves in the future.
“You just have to trust them...trust the medics to make the right decisions and um, we know that sometimes they do that and sometimes they don’t....But...there’s no point in getting stressed out about it.” M34, session 1

Ten patients said that they trusted the medical profession but would prefer that those decisions be made in conjunction with their family and friends.

“If there was a decision to be made and...there was a choice and the doctors really didn’t know which was best....if they’re making a decision in your best interests, that interest may well be served by...having your family involved in the discussions.” M33, session 1

ii) Options for making future health care decisions

The care planning mediator gave the Terrence Higgins Trust document to patients and informed them of the options for making future health care decisions – making an advance directive, a statement of wishes and preferences or appointing someone as a lasting power of attorney.

Eight patients said that they appreciated information about making future health care decisions and fourteen patients said that they wanted to make an advance directive. Seven patients said that their decisions about future treatments would depend on how things work out at the time. Regarding making a statement of wishes and preferences, one patient said,

“Those kinds of things, it’s hard to make them when you’re well.....because you’ve no idea what it feels like to be so weak....The difficulty is that when you’re feeling very well... feeling full of life....it’s hard to say ‘oh, yes, now when I die I would like this and that’.” M23, session 1

Eight patients said that they were limited by the fact that they did not know what treatment options are available in the future.

“It’s a bit easier to write a birth plan than to write or plan on something when I’ve got no idea what the options are...or what the problems will be.” M33, session 1

Seventeen patients said that they would be happy for their family to make decisions on their behalf if they were unable to make them. Twelve patients said that they had plans to talk to their relatives about future health care decisions at some point and thirteen patients said that they may appoint their relatives as a lasting power of attorney in the future.

Seven patients said that they will deal with this when they start to deteriorate as it would feel more appropriate at that stage.

“To be frank with you, it is too soon for me to think about that, and it’s not helpful for me now.... It is not that I won’t think about it....but there are still some decisions that I’m not ready for and that...area is one of them. Because of that need to...stay focused on living for as long as I can.” M24, session 1

iii) Talking to doctors about making future health care decisions

Eighteen patients said that they hadn’t talked to their doctors about their preferences for future health care. Six patients said that they did not wish to speak to their doctors about this subject at the moment but would talk more about their preferences if their condition were to deteriorate.
“I wouldn’t want to do it now.....Because at the moment I’m trying to plan for success rather than failure....But if failure becomes a likely option then I’ll switch to a different mode.” M33, session 1

iv) Quality-of-life more important than length of life
Sixteen patients said that quality of life is more important to them than length of life and they wouldn’t want to be kept alive at all costs if their quality of life was poor.

“The purpose of medicine is to alleviate suffering... It’s not about extending your life at any costs... There’s got to be quality of life.” M32, session 1

Five patients (13%) said that if they were dying, they would want to die peacefully and with dignity.

“Give me a graceful exit if you can and make it, not quick, but.... don’t prolong it just for the sake of it.” M43, session 1

v) Resuscitation
When asked for their views on resuscitation, half of the patients said that their views would vary depending on how ill they were and fifteen patients said that they would only want to be resuscitated if they were going to have some quality of life afterwards. Because of this, ten patients said that they would not want to be resuscitated if they were deteriorating generally, but only if they died suddenly.

5.1.9 General views expressed at the end of the discussion
i) Views on ACP discussion
When asked how they felt at the end of the discussion, one third of patients said that they had found the conversation very useful or helpful.

“I think it’s very useful possibly to have this conversation, because you do skim the surface of things quite often.... I can see the point of having a talk like this.” M23, session 1

Nine patients said that the discussion had given them new information, for example, information about preferred place of care, benefits, making advance decisions or symptom control. Even though some of the patients found it challenging to discuss the future, many found this information extremely valuable.

“There’s a bit of me that thinks ‘I don’t want to think about this, I don’t want to think about dying when I’m feeling well.... It’s not easy to talk about these things at all, but I think…all information is power.” M40, session 1

Twelve patients said that the discussion had been thought-provoking for them and six patients said that they knew they needed to think about the issues raised and plan or get things in place. Four patients (10%) said that the discussion had clarified some things that had been in the back of their minds or allayed their anxiety about a possible deterioration in health.

“It is practical and nice to have this uh, foreseeing of things. If I..were to fall ill now, I’d absolutely have no fear.” M23, session 1
Six patients said that having the discussion made them feel emotional. Eight patients said that they were not yet ready to address the issues associated with the end of life or they would address these issues at a more appropriate time.

“If you make people start thinking about these things, I’m not sure whether it helps.....Obviously one has to discuss it at some stage, but discussing it early, I’m not sure is a good thing .... If.. one starts discussing everything that could possibly go wrong and how you deal with it, I think it might have a negative impact on their prognosis.... It's made me think about things....I’ll keep it in the back of my mind and then if things get worse, I’ll, I’ll know what to do.... But I really don’t want to think about it. Most of the time I want to try and think positive.” M33, session 1

ii) Arranging another ACP discussion
When asked at the end of the first discussion whether they wanted to meet up again, seven patients said that they might like to meet again after thinking through some of the issues discussed.

“You suggested ... meeting on another couple of occasions .... I think that would be very good at that juncture, then perhaps some of what you've discussed will have moved on..... A series of steps.” M26, session 1

Seven patients said they wanted to meet again after seeing the doctor or getting scan results, four patients wanted to meet again if their health deteriorated and three patients (8%) wanted to meet again after reading through the living will document.

5.1.10 Differences between first and future sessions

i) Talking with health professionals about the future after ACP discussion
Eleven patients had more than one ACP discussion. Five of these took steps to talk to their health professionals about the future after the first discussion. Three patients who intended to ask their doctors about the future after the first session said that getting good news at their clinic appointment delayed them addressing issues regarding the future.
Fifteen patients said that they planned on talking to their doctors or nurses about the future after having the first advance care planning discussion. The areas that patients wanted to discuss included asking their doctor about prognosis, making future health care decisions, preferred place of care and the likely course of deterioration.

ii) Talking with close persons about the future after ACP discussion
A quarter of the patients said that they wanted to talk to family members about the future after the advance care planning discussion. Five patients said they wanted to talk to family members about making future health care decisions.

Five out of the eleven patients who had an additional discussion actually ended up talking to their partner or spouse about the future. The areas that were discussed were the living will document, preferred place of care, expected prognosis and the patient’s wishes concerning blood transfusions and resuscitation.

In two instances where the patient’s relative was present during the second ACP discussion, they talked about things that they hadn't communicated about before.
5.2 Qualitative data from brief interviews conducted at follow-up

Sixty six patients completed the follow-up interview (n=66). Three patients withdrew from study before follow-up and three patients were too ill or died before the follow-up interview. The following themes were identified from the qualitative questions asked at the eight week follow-up interview. (See Appendix H: Responses to Qualitative Questions at follow-up interview)

5.2.1 Views on advance care planning

Fifty six patients said that advance care planning is a good idea and a positive thing.

“Very important because it allows people to understand what’s happening, their options” P37

Forty one patients said it would be helpful or beneficial to discuss their future care with a health professional trained for that purpose.

“Yes it’s helpful – people don’t plan and don’t know what’s on offer.” P5

i) Value of ACP depends on individual

Twenty two patients said the ACP discussion may not be appropriate for everyone as patients vary in how much they want to know. Its value may be dependent on the individual and their circumstances.

“Might lead some people to panic and some people don’t like to be realistic. I like to know but other people might not.” P47

ii) Timing of ACP discussion important

Twelve patients said that the timing of the ACP discussion is important and there might be a more appropriate time to have this kind of discussion.

“At present my cancer is holding so don’t want to think about the future and plan for it. It would be helpful to see someone about planning, but only if my condition becomes worse.” P75

iii) Emotional subject and may be difficult for some people

Ten patients said that the ACP discussion may be upsetting or distressing for some people.

“Many patients don’t want to focus on the end…. Hard for people to cope with.” P76

Even when it may be difficult to discuss issues to do with the end of life, the discussion may still be beneficial.

“Was really upset after the interview. Thought I had worked it through but…it brought out a lot. “Found it difficult but helpful.” P76

iv) Important to be given information

Six patients identified the need to be given information, as patients do not always know what to ask for.

“Think there should be a named person who tells you things, medical issues…. I got the answers if I asked but I did not know what to ask. There is no organised information.” P1
v) **Skills of person conducting the ACP discussion**

Four patients said that it is important that the person conducting the discussion has the necessary skills for dealing with such sensitive issues.

“Think it could be distressing but it depends on how it’s done.” P24

The majority of patients (45) said their views of ACP had not changed since the baseline discussion.

5.2.2 **Advance directives**

Forty five patients said advance directives are a good idea/helpful, might help to focus the mind, empower patients and help make future decision making clearer and easier.

“A good idea if you can write down what you want so that it helps if you can’t make a decision at the time. Can take the burden off people in the future.” P21

“I think it can focus your mind which is the useful thing about it.” P23

“Helpful as empowers you.” P42

i) **Timing of completing advance directives**

Ten patients said they were not at the stage where they felt they needed to complete an advance directive. As with advance care planning, a number of patients said that there is an appropriate time to complete an advance directive and this would usually be when someone’s condition worsens.

“I think advance directives are good and will pursue this when my condition gets worse.” P75

ii) **Potential problems with advance directives.**

27 patients identified potential problems with advance directives.

- Twelve patients were concerned about a person changing their mind after documenting a view.
  “If somebody forms a view and then changes their mind then this could be a problem.” P2
- Five patients said it could be difficult if a relative and patient want different things.
  “Might be hard if your family was against it.” P76
- Three patients said there is a possibility of being misunderstood.
- Two patients said that it is hard not knowing what the options for treatment are.
  “Main issue is knowing the options – need to be informed by doctor of options.” P42

Three patients said that they were now better informed about advance directives than they were at the baseline discussion.

5.2.3 **Satisfaction with relationships - health professionals**

Patients expressed differing views on their satisfaction with their relationship with health professionals. Forty three patients were satisfied with these relationships.

“Very satisfied with all these relationships.” P23

Ten patients said that they are not satisfied with their relationships with their health professionals. The reasons for this were feeling that the information they wanted was not
being given, communication with the doctor was poor and there was a lack of time in the consultation to talk about all that they wanted to discuss.

“The information was not really available and I had to find it out myself.” P6

“I would like more time with the doctor….Small things would like to ask but I am conscious of the pressure on the doctors.” P18

5.3 Qualitative Data collected on reasons for expressed preferences for or against receiving the ACP discussion intervention

All patients were asked to choose whether they wanted to receive the ACP intervention, usual care or were happy to be randomized and have a 50% chance of receiving the intervention or usual care. They were also asked to state their preference for having the ACP intervention on a scale. However, their choice of group was an independent decision and their strength of preference on the scale did not determine which group they were allocated to.

At baseline, patients were asked if there were any reasons that they answered the way that they did on the strength of preference scale. If they gave a strong preference either way, they were asked why. Data were available on 72 participants. The responses are summarized below.

5.3.1 Interest in ACP study
- Thirteen said that the ACP study sounds interesting or that ACP is a good idea.

5.3.2 The need for information and to talk about the future
- Nine patients said that they needed/wanted information about the future.
- Sixteen patients said that they wanted to talk about the future/clarify things and plan. One patient said that s/he wanted to make his/her wishes clear regarding the end of life so that things aren’t left to chance.

5.3.3. Desire to help with research
- Nine patients said that they wanted to help others/Marie Curie through taking part in the research.
- Eighteen patients said that they were happy to take part or to help out with the research.

5.3.4 Usual care, intervention group or randomization group
- Eighteen patients said that they didn’t mind which group they were put in. One patient said that s/he already has support and so doesn’t mind which group s/he was put in. One patient had made a will and future plans so did not mind which group s/he was put in.
- Nineteen patients said that they wanted to do ACP intervention.
- Fifteen patients said that they wanted to have usual care/didn’t want to have the ACP intervention. Four patients said that they had no time to do the ACP intervention, one patient lived too far away and one patient didn’t want to do the intervention without his wife there for every session. Four patients said that they already had support so did not feel the need to have the ACP intervention.
- Five patients said that they had a slight preference for a particular group but were happy to be randomized.
5.4 Feedback from clinicians about the ACP study

Two consultant medical oncologists, one from each of the participating hospitals provided some feedback on their views about the ACP study once the study had been completed. The consultants were sent a brief questionnaire designed to elicit their views on their role in referring patients they thought met the criteria for entry into the study and recruitment issues.

The consultants were asked what their initial thoughts/feelings about the ACP study when they were first introduced to the idea. This resulted in two very different responses.

Clinician 1: ‘Extremely enthusiastic because I believe that this kind of research in a UK setting is critical’

Clinician 2: ‘that it meant telling patients that they were doomed.’

They were also asked regarding their feelings about referring patients to the study and whether they had any concerns about making referrals. There were two quite different responses to this line of enquiry.

Clinician 1: ‘No issues provided clinical opinion was sought first regarding the suitability of patients for the study,’

Clinician 2: ‘once I had learned that patients were to be approached in a very tactful way, it was ok.’

Interestingly, neither consultant reported any feedback or conversations about the study from patients that they had referred.

We asked whether they had any suggestions for ways in which researchers can recruit patients more efficiently into studies. One suggested

‘the key is to have a nursing presence in clinics. This is not always that productive but it does serve to remind clinicians that such trials are open to recruitment,’

and the other felt it was,

‘laborious for the recruiters but I don’t think there is a shortcut.’

Both consultants reported that they were very positive about being prepared to refer patients in the future to similar studies run by the Marie Curie research unit at UCL. Finally, they were asked whether they had any further comments to make about the study, neither had any further comments.

5.5 Research staff reflections

The two researchers who worked directly with the patients on this study were asked to reflect on their experiences. Several issues were raised including:
1. Gate-keeping by health care professionals.
2. Patients becoming emotional.
3. Patients reactions to use of the words ‘advanced illness’ on the patient information sheet.
6. Discussion
Addressing end of life treatments with patients who suffer life-threatening conditions such as cancer is a delicate task. Evidence to date would suggest that most patients and their carers would prefer to undertake open ended discussion with health professionals rather than considering completion of advance directives or written care plans. Thus, in this research we assumed that an informal discussion would be the most acceptable approach to study in depth. Our aims were to assess whether the effectiveness of advance care planning discussions could be evaluated in a randomised trial and to decide on the most appropriate outcomes to measure. We have presented our results in some detail given that this is a feasibility study and given that we were uncertain of the most pertinent outcome.

6.1 Main Findings
We have shown that asking patients with recurrent progressive cancer to take part in a trial of an advance care planning (ACP) discussion does not cause significant distress. Recruitment to the study was limited by the need for clinicians to assess whether they thought that patients were ready to confront issues raised by the research. Of those patients then approached by the research team, 77 out of 180 (less than half) agreed to take part. Despite this recruitment rate, attrition was very low and anxiety and depression were not affected by participating in the study suggesting that participants were not adversely affected. This is in accordance with recent work conducted in Australia with 174 terminally ill cancer patients which evaluated an RCT of a prompt list to encourage patient question-asking about prognosis and end-of-life care. This study also found no significant changes in patient anxiety (Clayton et al., 2007).

Although most of our participants showed some preference for the intervention, a small number, mostly from lower socio-economic groups and those educated to school level only, showed preferences for usual care. Reasons for preferring usual care included lack of time to engage in the intervention, living too far away, wanting their partner present at every session which was outside protocol and, for some patients, the perception that they were in receipt of enough support and therefore did not need the ACP intervention.

The study design allowed for the inclusion of small numbers as is usual in a feasibility trial. Given that we were testing an informal discussion, deciding on outcomes was a complex process. We developed visual analogue scales to measure our main outcomes as these are useful in measuring change and standardised instruments were not available. We have shown that individual questions posed could be grouped into three overall domains the responses to each of which had satisfactory internal consistency and therefore could be summed and treated as overall outcomes. Within these limitations, we noted that levels of communication with health care professionals, satisfaction with support and overall communication were higher in those receiving usual care, although not reaching statistical significance. Indeed there were no significant differences in patient satisfaction with communication in any group, which again reflects the work of Clayton et al., (2007), who found that encouraging question-asking about prognosis and end-of-life care did not impair satisfaction with communication.

We found that discussion about future care occurred more frequently in those receiving the ACP intervention, increased with duration of illness and was more common amongst men than women. Findings in the preference cohort did not mirror those in the randomised cohort except in the domain general satisfaction with services and overall discussion about future care. Although the results from the preference cohort should be interpreted with caution as there was no randomisation, we did observe some interesting findings. Assuming that a statistical level of significance of 0.2 is indicative of an important trend, the main changes in the preference cohort were towards less happiness with communication with professionals and lower general satisfaction, coupled with a higher likelihood of having had advance care planning discussions with professionals (Table 4.9). These findings are perplexing but may
suggest that expectations were raised in the group receiving the intervention and might imply that the ACP discussion sensitised each patient to how much communication could be improved. That is to say that the ACP discussion made them realise how little say they were having in terms of treatment planning, which led to a decrease in satisfaction. There were no important trends in the randomised cohort. Because of the differences in the direction of findings in the preference and randomise cohorts, combining the cohorts tended to reduce the point estimates of our findings. However, the small numbers necessarily limit our interpretation of these findings.

For most of the patients receiving the ACP discussion, just one session with the care planning mediator appeared to be enough to meet their needs. Many of the patients found the discussion useful or thought-provoking, but there was also a sense that those with cancer need to be able to get on with life as normal and not focus extensively on planning for the end of life. These results are similar to those found in a previous study (Barnes et al., 2007) where an obvious tension was identified between wanting to get on with life as normal and considering end of life issues.

This study has built substantially on earlier work conducted in the UK (Horne et al., 2006), by putting an ACP intervention in the context of a randomised trial. The considerably larger sample size obtained overall and the substantial number of ACP interviews conducted provides very rich data on the ACP process. This work, however, agrees with that of Horne et al., (2006), in that patients’ responses to the subject varied although some did welcome the opportunity to document their wishes and preferences.

Most patients had not spoken extensively to either their doctors or those closest to them about a future deterioration in health. It appears that although there were certain issues patients did wish to talk about, for many, the timing may not have been right for a more thorough discussion with health professionals and family members on topics such as the dying process or preferred place of care. With regards to timing in this study we were guided by our phase I work (Barnes et al 2007) and approached patients who had been diagnosed with advanced cancer with active progressive disease. Although we do not know exactly how much time had elapsed between diagnosis and before enrolment into the study, a systematic review published at the time we completed recruitment recommends that a discussion of the prognosis and ACP should occur within a month of the patient’s new diagnosis of advanced cancer (Walling et al., 2008). This suggests that the timing of recruitment into the study was appropriate.

Our results on completion of or intention to complete an advance directive are inconclusive and raise concerns that some patients were confused over terminology. Some of those who reported having completed advance directives at baseline did not confirm this at follow up and this raises concerns that there was confusion over terminology. A recent systematic review identified that the provision of oral information over multiple sessions is a successful way to encourage people to communicate their preferences regarding future healthcare (Bravo et al., 2008). It has also been found that education alone does not increase the likelihood of completing advance directives, rather that the important component of any ACP intervention is providing the opportunity for patients to ask questions (Jezewski et al., 2007). We found that the majority of patients who completed the ACP discussion (95%) indicated that they had not spoken extensively to their doctors about the future or what might happen when their health deteriorated. This lack of communication between doctors and patients regarding both the appropriateness and purpose of advance directives may partially explain why completion rates are low. Patients believe it is the doctors’ responsibility to instigate discussions about advance directives, whereas most doctors believe the responsibility lies with the patient (Johnston et al., 1995).
Many patients said that they wanted more information from their doctors about certain issues to do with the future, but the doctors’ reluctance to talk about the future as well as the lack of time in clinic appointments meant that this information was not readily available. It appears that many patients were not aware of the options available to enable them to be cared for in a place of their choice when their health deteriorated. A large number of patients did have a preference to be cared for in their own home, but concerns about being a burden on those closest to them and a lack of awareness of the support that was available in the community both influenced whether patients consider their preference to be a likely possibility. This highlights the need to provide patients with more information about what support is available to enable them to be cared for in their preferred place of care. It has long been acknowledged that although many patients express a desire for information they seldom attempt to obtain it during medical visits (Beisecker, 1990; Beisecker & Beisecker, 1990). This appears to be unrelated to the information seeking or information giving behaviour of the doctor (Waitzkin, 1985).

We encountered some resistance from clinical staff to introducing this research to patients. Such gate-keeping is common in palliative care research, but the topic of this study was particularly sensitive. Researchers were able to approach only patients who had been identified by clinicians as suitable for the study by virtue of the stage of their disease and by their considered suitability to deal with the concept of planning for future care and their awareness of the extent of their illness. Despite these filters, analysis of the qualitative data revealed wide variation in the readiness of patients to consider many of the issues raised by the discussion schedule. These results are of particular importance given the sensitivity with which our sample was recruited and our attention both to clinicians’ views and to patient preferences. This evidence should be heeded by practitioners who are currently being encouraged by policy makers, End of Life Care Strategy, the Gold Standards Framework, and the introduction of guidelines such as those recently published by the Royal College of Physicians to introduce ACP discussion for all patients thought to be in the last year of life.

Overall it was our impression that clinicians and other clinic staff underestimated the ability of patients to deal with research studies of this nature and we found that patients were generally happy to be approached if this was done in a gentle and compassionate manner. Some clinicians (nurses in particular) appeared very protective of their patients and were often reluctant to consider referring them to the research team. This suggests that, if ACP were to become a routine option, patient care might vary widely with the attitudes of clinicians who might or might not allow an independent mediator to talk to the patient. It may also have implications for the content of clinical discussions which may still avoid the issues of planning for the future.

On rare occasions a patient became upset when we introduced the study to them. This occurred for a variety of reasons. Sometimes patients might leap to the conclusion that their consultant had suggested that they were suitable for the researcher to approach them as they were dying and that this had been concealed from them. Sometimes patients felt that they did not want to be reminded that they had cancer and did not wish to talk about it. On a few occasions the patient reacted adversely to the words ‘advanced illness,’ which was part of the study title on the participant information sheet that had been approved by the research ethics committee. Talking to the patients could be difficult if patients had dominant spouses or family. We felt that in some circumstances it was more difficult to get the real view of the patient with their family present and sometimes family members tried to answer questions for the patients. In our view ACP needs to be conducted initially one-to-one with the patient alone, although family members may be invited to subsequent sessions at patients’ request. This may be difficult to achieve without causing offence to family members or causing them to become suspicious of a process that may have consequences for them.
The feedback received from two consultant oncologists who referred patients was very positive although one initially showed some concern ‘that it meant telling patients that they were doomed.’ However, that consultant was reassured once it had been explained how the researchers approached the patients. Interestingly, neither consultant reported any feedback or conversations about the study from patients that they had referred. This suggests that approaching a large number of patients did not raise any issues that caused sufficient concern for them to be mentioned. Both consultants reported that they were very positive about being prepared to refer patients in the future to similar studies run by the Marie Curie research unit at UCL.

6.2 Limitations of the study
This work was designed to assess the feasibility of an intervention derived from and grounded in phase I work. Although we recorded the content of the intervention in detail and analysed these data qualitatively, we did not attempt to quantify its acceptability to patients. However, the discussion schedule and qualitative findings provide a rich source of information on the nature of topics patients were willing and keen to discuss. Although guidance for ACP is currently available (most recently by the Royal College of Physicians) we feel that this study provides vital and new evidence both to underpin any future policy documents and to challenge widely held assumptions in this area.

6.3 Implications
We conclude that the effectiveness of advance care planning discussions can be assessed in a randomised trial. Although we aimed to examine trial participation and outcomes within a preference cohort, we would not recommend that this was adopted in a large-scale trial because it appears that patients who are eager to either undertake or avoid ACP discussions may differ substantially from those prepared to be randomised. Findings from other patient preference trials tend to indicate that, although there can be differences in outcome due to preferences, findings are similar in preference and randomised cohorts (King et al., 2000). It would seem that this may not be true in this field possibly due to the sensitive nature of a request for ACP. However, given that our numbers are so small we cannot make definitive conclusions on this point.

Our aim was to demonstrate whether such discussions lead to increased satisfaction with communication with professionals and family and friends, more frequent discussion with health professionals and family about preferred care near the end of life, and general satisfaction. Our paradoxical findings on these points by which our intervention appeared to reduce satisfaction possibly by increasing expectations leads us to think that increasing the frequency of discussions with health professionals and family and friends about preferred care were patients to become ill might be of benefit, and is likely to be the key outcome for a major trial.
7. References


8. Appendices

Appendix A: Measures
Appendix B: Terrence Higgins Trust Living Will
Appendix C: Information Sheets
Appendix D: Consent Forms
Appendix E: Advance Care Planning Discussion Schedule
Appendix F: Views of the care planning mediator on relatives being present during the discussion
Appendix G: Summary of Main Themes from ACP discussions
Appendix H: Responses to qualitative questionnaires at follow up interview
Appendix A: Measures

1. Patient Questionnaire: Section A - Demographic details
2. Patient Questionnaire: Section B
3. Strength of Preference Scale
4. Hospital Anxiety and Depression Scale (HADS)
5. Karnofsky Performance Status Scale
6. Patient Interview: Reasons for preference (Baseline)
7. Patient Interview (Follow-up)
8. Interview Questions for Health Professionals
1. Patient Questionnaire: Section A - Demographic details

We would be grateful if you could complete the following questions.

1. What is your gender?  □ Male  □ Female
2. What is your date of birth?
   (day/month/year): .................................................................
3. What is your marital status?
   □ Married  □ Divorced/Separated  □ Partner – living with
   □ Single, never married  □ Widowed  □ Partner – not living with
   □ Other (Please specify ..........................................................)
4. How would you describe yourself?
   □ White  □ Black Caribbean  □ Bangladeshi
   □ Black British  □ Indian  □ Chinese
   □ Black African  □ Pakistani  □ Other
   (Please specify ..........................................................)
5. What is your employment status?
   □ Employed  □ Self employed  □ Unemployed seeking work
   □ Home manager  □ Retired  □ On sick leave
   □ Student  □ Other (Please specify ........................................)
   a) If you are in paid employment, can you describe your work?
   ..................................................................................................................
   b) If you are not in paid employment now, what was your last job?
   ..................................................................................................................
6. What is the highest level of education you have completed?
   ..................................................................................................................
7. Do you observe a specific religion?

- I do not observe a religion
- Christianity - Roman Catholic
- Christianity - Protestant
- Christianity - Orthodox
- Christianity - other
- Islam
- Buddhism
- Sikhism
- Judaism
- Hinduism
- Other -
  (Please specify …………………………………………………………………………..)

8. What is your diagnosis?

……………………………………………………………………………………………………

9. What year were you diagnosed?

……………………………………………………………………………………………………
2. Patient Questionnaire: Section B

Please read through each statement and circle the response that best describes your view.

1. I am happy with the level of communication I currently have with my doctors at the hospital

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

2. I am happy with the level of communication I currently have with the nurses at the hospital

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

3. Is there another health professional who is very involved in your care?

☐ No        ☐ Yes

(Go to question 5) (Please specify who)

4. I am happy with the level of communication I currently have with this health professional (question 3)

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

5. I am happy with the level of communication I currently have with my close family

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

6. I am happy with the level of communication I currently have with my close friends

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
7. I have talked with my doctors at the hospital about the care I would prefer if I were to become very ill

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

8. I have talked with the nurses at the hospital about the care I would prefer if I were to become very ill

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

9. I have talked with my GP about the care I would prefer if I were to become very ill

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

10. Are there other health professionals who you have talked with about the care you would prefer if you were to become very ill?

○ No  ○ Yes

(Please specify who ............................................................)

11. I have talked with my close family about the care I would prefer if I were to become very ill

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

12. I have talked with my close friends about the care I would prefer if I were to become very ill

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

13. I am a spiritual person

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

14. Prior to taking part in this study, I had heard of advance directives or living wills

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
15. Prior to taking part in this study, I was aware what an advance directive or living will is

<table>
<thead>
<tr>
<th>Very strongly disagree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

16. I intend to complete an advance directive/living will

- [ ] Yes  - [ ] No  - [ ] Unsure  - [ ] Have already completed one

17. Overall have you felt satisfied with your health care?

<table>
<thead>
<tr>
<th>Dissatisfied</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

18. Overall have you been satisfied with how the different parts of your health care (e.g. chemotherapy, radiotherapy, surgery) have been co-ordinated?

<table>
<thead>
<tr>
<th>Dissatisfied</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

19. Overall have you been satisfied with the level of support provided by the health care services?

<table>
<thead>
<tr>
<th>Dissatisfied</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

20. Overall do you feel satisfied with the information you received about your illness?

<table>
<thead>
<tr>
<th>Dissatisfied</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

21. Overall have you felt satisfied with the way health care professionals communicate with you?

<table>
<thead>
<tr>
<th>Dissatisfied</th>
<th>Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

22. Overall have you felt confident in the health care professionals looking after you?

<table>
<thead>
<tr>
<th>Not confident</th>
<th>Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
3. Strength of Preference Scale

In an advance care planning discussion, you are given an opportunity to discuss your experiences of care; your current problems and concerns, including finances; your fears for the future and preferences that you may have about future care. You are also given an opportunity to complete a written advance statement, in which you may document what treatment you wouldn’t want if you were to lose the ability to make decisions in the future. You can also appoint someone to make decisions on your behalf if you were to reach a stage where you were unable to make decisions yourself.

Strong preference
to receive usual care

5 4 3 2 1 0 1 2 3 4 5

Please place a mark through the line to determine your preference towards receiving either the advance care planning discussion or receiving usual care. ‘Usual care’ in this study refers to the care you would receive regardless of whether you enter the trial. The stronger your preference to either condition, the higher number on the line should be marked. If you place a line through the 0 in the middle it will be assumed you have no preference either way.
4. Hospital Anxiety and Depression Scale (HADS)

This questionnaire is designed to help us know how you feel. Read each item and tick the box opposite the reply which comes closest to how you have been feeling in the past week. Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or ‘wound up’:
Most of the time........................................
A lot of the time......................................
Time to time, occasionally......................
Not at all...............................................  

I still enjoy the things I used to enjoy:
Definitely as much.............................
Not quite as much...............................
Only a little........................................
Hardly at all........................................  

I get a sort of frightened feeling as if something awful is about to happen:
Very definitely & quite badly...............  
Yes, but not too badly........................
A little, but it doesn’t worry me............
Not at all...............................................  

I can laugh at the funny side of things:
As much as I always could..................
Not quite so much now.......................
Definitely not so much now...............  
Not at all...............................................  

Worrying thoughts go through my mind:
A great deal of the time.....................
A lot of the time...............................  
From time to time but not often..........  
Only occasionally.............................  

I feel cheerful:
Not at all............................................
Not often............................................
Sometimes........................................
Most of the time...............................  

I can sit at ease and feel relaxed:
Definitely..........................................  
Usually..............................................
Not often..........................................  
Not at all.............................................  

I feel as if I am slowed down:
Nearly all the time................................  
Very often..........................................  
Sometimes........................................  
Not at all..........................................
I get a sort of frightened feeling like ‘butterflies’ in the stomach:
Not at all........................................
Occasionally...................................
Quite often......................................
Very often........................................

I have lost interest in my appearance:
Definitely........................................
I don’t take as much care as I should.
I may not take quite as much care.....
I take just as much care as ever........

I feel restless as if I have to be on the move:
Very much indeed.............................
Quite a lot........................................
Not very much...................................
Not at all...........................................

I look forward with enjoyment to things:
As much as I ever did.......................  
Rather less than I used to.................
Definitely less than I used to.............
Hardly at all.....................................

I get sudden feelings of panic:
Very often indeed.............................
Quite often......................................
Not very often..................................
Not at all........................................

I can enjoy a good book or radio or TV programme:
Often..............................................
Sometimes......................................
Not often.......................................  
Seldom..........................................
5. Karnofsky Performance Status Scale
Definitions Rating (%) Criteria

To be completed by the researcher at baseline and at follow-up.

Study number ……………………………………. Date ………………………………

Baseline □ Follow-up □

Please circle the response that best describes the patient on the day of assessment.

<table>
<thead>
<tr>
<th>Ratings</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Normal no complaints; no evidence of disease.</td>
</tr>
<tr>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease.</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease.</td>
</tr>
<tr>
<td>70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most of his personal needs.</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care.</td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance.</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated although death not imminent.</td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary.</td>
</tr>
<tr>
<td>10</td>
<td>Moribund; fatal processes progressing rapidly.</td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
</tr>
</tbody>
</table>
6. Patient Interview: Reasons for preference (Baseline)

I would like to ask you a number of questions.

Reasons for preference
We have already asked you to indicate whether you have a strong preference for either receiving the advance care planning discussion or not.

- Were there any reasons you answered the way you did?
- If you gave a strong preference either way, can you tell me why?

........................................................................................................................................
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7. Patient Interview (Follow-up)

1. Clinical condition and receipt of care
   - Have there been any changes in your health since we last met?
   - How are you feeling physically?
   - What medical care/treatment have you received since we last met?
   - Have you started any new medical care or treatment since we last met?
   - Have you been referred to any different health professionals since we last met? Who? Can you tell me more about this?

2. Views on advance care planning
   - How do you feel about advance care planning now?
   - Have your views changed at all since we last met? How have they changed?
   - Do you think it would be helpful for patients to discuss their future care with a health professional trained for that purpose?
   - Do you have any concerns about advance care planning?
3. Views on advance directives

- What do you think about advance directives now?
- Have your views changed at all since we last met? How have they changed?
- Do you think advance directives are helpful or unhelpful?
- Do you foresee any particular problems with advance directives?

4. Relationships with close persons and professionals

- Has your relationship with your doctor changed at all since we last met? Has it got better? Or worse?
- How about your relationship with your nurses or other health professionals? And with close family? And close friends?
- Have you found communication with your doctor easy or hard in the last few weeks? Can you tell me more about this?
- And communication with your nurses or other health professionals involved in your care? And with close family? And close friends?
- Do you feel satisfied with these relationships? Can you tell me more about this?
Appendix B: Terrence Higgins Trust Living Will

Living Will
Fourth Edition
Before you fill in your Living Will, please read all these notes carefully.

**What is a Living Will?**

A Living Will is an advance directive that you can make to specify your wishes about medical treatment. It is important to consult with your doctor and legal advisor to ensure that your Living Will is valid and enforceable in your jurisdiction.

**Discussing your Living Will with others.**

Discussing your Living Will with others is important to ensure that your wishes are known and respected. It is recommended to include your family, friends, and healthcare providers in the discussion.

**Answered.**

If you have certain values or preferences that are important to you, it is important to communicate these to your healthcare providers and family members. They can help ensure that your wishes are respected and that your Living Will is effective.

**Medical treatment in general.**

Medical treatment is generally provided to maintain life, not to cure or improve health. If your wishes are not clear, it is important to consult with your healthcare providers and legal advisor to ensure that your wishes are respected.

**What happens if you change your mind?**

If you change your mind, it is important to notify your healthcare providers and legal advisor. They can help ensure that your wishes are respected and that your Living Will is effective.

**How to fill in the Living Will form.**

The following steps are suggested: you fill in the form with your own words. It is important to consult with your healthcare providers and legal advisor to ensure that your wishes are respected and that your Living Will is effective.

**Conclusion.**

Your wishes should be clear and specific to ensure that they are respected. It is important to consult with your healthcare providers and legal advisor to ensure that your wishes are respected and that your Living Will is effective.
Particular treatments or tests

2. If you have any concerns about particular types of medical treatment or tests, you should ask them here. For example, you might wish to avoid certain brands of medication or tests for religious reasons. Please discuss these worries with a member of the team before you fill in the form. It is important that the person filling in the form is fully aware of any concerns you may have.

3. If you want to refuse a particular treatment or test, you should state this clearly on the form. It will be taken into account when you come for your actual treatment or test.

4. If you wish to discuss a medical treatment or test with your doctor, you should consult your doctor before filling in the form. It is important that you understand all the implications of your decision.

5. The form requires you to write your views about medical treatment and test.

Having a friend or relative with you

If any of you have a friend or relative with you, you can discuss your concerns with them. It is important that they understand your views and are able to support you.

If you are under 18 years of age, you should bring a friend or relative with you to the meeting.
This is an important document. Before you fill it in, please read the notes which are attached to this form. We recommend that you discuss your Living Will with a doctor, but you do not have to.

Living Will declaration

Your details

I make this Living Will to record my wishes in case I become unable to communicate, and cannot take part in decisions about my medical care.

Name:
Address:

Daytime phone number: __________________ Evening phone number: __________________

If you discuss this Living Will with a doctor before or after you fill it in, please fill in this section.

I have discussed this Living Will with the following doctor:

Doctor's name:
Doctor's address:

Doctor's phone number:
Living Will Advance directives

1 Medical treatment in general

Three possible health conditions are described below.
For each condition, choose "A" or "B" by ticking the appropriate box, or leave both boxes blank if you have no preference. The choice between "A" or "B" is exactly the same in each case.
Treat each case separately. You do not have to make the same choice for each case.

I declare that my wishes concerning medical treatment are as follows.

Case 1
Possible terminal condition

Here are my wishes if:

- I have a terminal illness from which there is no possibility of recovery.
- I wish to specify that my life should be ended in case:

A. I want to be kept alive for as long as a reasonable passage
B. I prefer not to be kept alive by medical treatment. I want medical treatment to be halted

In both cases, I understand and freely accept that medical treatment is halted.

Case 2
Permanent mental impairment

Here are my wishes if:

- I am unable to sustain a permanent mental impairment.
- I am unable to sustain a permanent mental impairment from a mental illness and am not responding to treatment.

A. I want to be kept alive for as long as medically necessary, if medical treatment is available.
B. I do not want to be kept alive for as long as medically necessary if medical treatment is available.

Case 3
Permanent uncooperative

Here are my wishes if:

- I am permanently unconscious or am not mentally aware and will remain incapacitated.
- I wish to be kept alive for as long as medically necessary by medical treatment.

A. I want to be kept alive for as long as necessary
B. I do not want to be kept alive by medical treatment. I want medical treatment to be halted

I understand and freely accept that medical treatment is halted.
## Living Will Advance directives

### 2 Particular treatments or tests

If you have any wishes about particular medical treatments or tests, you can record them here. If you want to refuse a particular treatment or test, you should say so clearly. This is where to write your views about treatment or tests while you are pregnant. You should speak to a doctor before you write anything in this space.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>

### 3 Having a friend or relative with you if your life is in danger

You can fill in this section if you would like a particular person to be with you if your life is in danger. It may not be possible to contact the person you name, or for him or her to arrive in time.

**If my life is in danger, I want the following person to be contacted to give him or her a chance to be with me before I die.**

<table>
<thead>
<tr>
<th>Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Daytime phone number:</th>
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<th>Evening phone number:</th>
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Idea: If you fill in this number or have this person to be contacted to give him or her a chance to be with me before I die.

If you fill in a name, it may not be possible to contact the person, or for him or her to arrive in time.

If you fill in a number, it may not be possible to contact the person, or for him or her to arrive in time.

Section 4 - Particular instructions or tasks may be temporarily suspended. This is where you fill in the answer with this form.
Living Will Health care proxy

I appoint the following person to take part in decisions about my medical care on my behalf and to represent my views about the decisions if I am unable to do so. I want him or her to be consulted about and involved in those decisions and I want anyone who is caring for me to respect the views he or she expresses on my behalf.

Name: 
Address: 

Daytime phone number: 
Evening phone number: 

Signatures

This Living Will remains effective until I make clear that my wishes have changed.

Sign and date the form here in the presence of a witness:

Your signatures: 
Date: / / 

The witness must sign here after you have signed the form.

The witness should then print his or her name and address in the spaces provided.

Please note the witness must not be a doctor and should not be a legal professional.

Signature of witness: 
Name of witness: 
Address of witness: 

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Participant Information Sheet A (patient – preference arm open)

Study title
Study to explore planning of future care with patients with advanced illness and to determine how we measure the effectiveness of these discussions.

Invitation paragraph
You are being asked to take part in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information and discuss it with others if you wish. If there is anything that is unclear, or if you would like some more information, please feel free to contact us. Thank you for taking the time to read this.

What is the purpose of the study?
Patients do not always feel that their wishes regarding their care are adequately considered by health professionals. This is particularly important for those patients with potentially life-threatening illnesses. Patients vary in the amount of information they wish to receive at different stages of their illness. However, some patients have many fears about the future and would welcome the opportunity to discuss the options that are available to them. In particular, they may wish to discuss the future conduct of their care should a time arrive when they are no longer able to make decisions about their treatment. This is known as advance care planning.

In previous work, we developed a number of questions to form the basis of discussions to help health professionals talk with patients about advance care planning. The purpose of this study is to explore how acceptable these advance care planning discussions are and what difference they make to patients. The study will be taking place over two years.

Why have I been chosen?
You have been asked to take part because you are a patient at the Royal Free Hospital, University College London Hospital or at Edenhall. We will be involving eighty participants in the study and are interested in the opinions and experiences of people of all ages and backgrounds.

Do I have to take part?
No, it is up to you to decide whether or not to take part. Your decision will not in any way affect the care that you receive. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the care that you receive.

What will happen to me if I take part?
You will be given this information sheet to take away and consider. You will also be given a consent form to sign if you decide to take part. You can return the consent form to us in the stamped addressed envelope provided. Once the research nurse receives your signed consent form, she will ask you whether you would be interested in undertaking an advance care planning discussion.
What is an advance care planning discussion?
In an advance care planning discussion, you would meet with a trained health professional (a care planning mediator) in a place of your choice, either in your home or in the hospital. You would be given an opportunity to discuss your previous experiences of care; your current problems and concerns; your fears for the future and preferences that you may have about future care; any financial concerns you may have and the preparation of a last will. You would also be given an opportunity to complete a written advance directive. In an advance directive you can document what treatment you would not want if you were to lose the ability to make those decisions in the future. You can also appoint someone to make decisions on your behalf if you were to reach a stage where you were unable to make decisions yourself. The whole discussion would last no more than one hour and you would be given the opportunity of meeting with the care planning mediator for up to two further sessions. These discussions will be audio-taped so that our research team can examine the range and development of topics covered in the discussion and how these change with time.

If you have a strong preference TO undertake this advance care planning discussion, you will be able to choose this option. If you have a strong preference NOT to undertake this discussion you will be able to choose this option. The research nurse will ask you to indicate how you feel about completing an advance care planning discussion by marking your strength of preference on a simple scale.

If you do not have a strong preference, you will be assigned to one of two groups. Those assigned to Group 1 will receive the advance care planning discussion plus usual care given by the Royal Free Hospital. Those assigned to Group 2 will not receive the advance care planning discussion, but will continue to receive the usual care given by the Royal Free Hospital. Neither you nor the researcher chooses which group you will be assigned to; it is decided on a random basis and you have an equal chance of being assigned to either of the two groups.

Whichever group you are allocated to, soon after you have given your consent to take part in this study, you will be asked to complete a number of questionnaires and a short interview with the research nurse, asking about your feelings, your level of satisfaction with your care, whether you feel able to talk openly with your doctor and family about your care and a small number of questions about advance care planning. You will be asked these questions again after six weeks.

What are the possible disadvantages of taking part?
If you are assigned to receive the advance care planning discussion, you will be talking in some detail about your future care and any concerns that you may have. This can be a sensitive area to discuss and some people may find it distressing to talk about these issues. Whichever group you are assigned to, you will need to complete a number of questionnaires and talk to the research nurse about your feelings, your care and some issues relating to the future. Some people may find it upsetting to talk about these things.

What are the possible benefits of taking part?
Patients who are given the opportunity to talk about the future and plan certain aspects of their care may find these discussions helpful. If you are not assigned to the advance care planning discussion group, there may be no immediate benefit to you. However, your participation in this research study will help us to understand better how we may develop ways of helping health care professionals discuss advance care planning with patients in the future. We hope that this will enable us to provide the very best care for people with life threatening illnesses. You may wish to raise some of your concerns about your care that this research might highlight with your usual clinical team.

What if something goes wrong?
If you are harmed by taking part in this research study, UCL has non-negligent (“no-fault”) indemnity arrangements in place. If you are harmed due to someone’s negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.
Will my taking part in this study be kept confidential?
All information collected will be kept strictly confidential. The advance care planning discussion will be audio taped. You will be given a personal number that will be used when the tape is transcribed. This will ensure that your comments are anonymous. Any comments that you make to the researchers will be kept confidential. If at any time the researchers are worried about your condition, they may ask your permission to pass on their concerns to a member of the clinical team responsible for your care. With your permission, the researchers will also inform your GP of your participation in the study.

What will happen to the results of the research study?
The findings of the study will be published in medical journals and presented at academic meetings. We anticipate that the results will be available by 2009. If you would like a copy of the results, please contact Dr Louise Jones, Head of Marie Curie Palliative Care Research Unit, Department of Mental Health Sciences, Royal Free & University College Medical School, Rowland Hill Street, London NW3 2PF. Your name, identity or personal details will not be revealed in any publication.

Who is funding the research?
The research is being funded by Dimbleby Cancer Care.

Who has reviewed the research?
The study has been reviewed by the Royal Free Hospital and Medical School Local Research Ethics Committee.

Contact for further information
If you would like to discuss any details of the project further, please feel free to contact Cate Barlow, Research Fellow, Marie Curie Palliative Care Research Unit on 020 7794 0500 ext 33714.

Thank you for considering taking part in this study.
Participant Information Sheet B (patient – randomisation only)

Study title
Study to explore planning of future care with patients with advanced illness and to determine how we measure the effectiveness of these discussions.

Invitation paragraph
You are being asked to take part in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information and discuss it with others if you wish. If there is anything that is unclear, or if you would like some more information, please feel free to contact us. Thank you for taking the time to read this.

What is the purpose of the study?
Patients do not always feel that their wishes regarding their care are adequately considered by health professionals. This is particularly important for those patients with potentially life-threatening illnesses. Patients vary in the amount of information they wish to receive at different stages of their illness. However, some patients have many fears about the future and would welcome the opportunity to discuss the options that are available to them. In particular, they may wish to discuss the future conduct of their care should a time arrive when they are no longer able to make decisions about their treatment. This is known as advance care planning.

In previous work, we developed a number of questions to form the basis of discussions to help health professionals talk with patients about advance care planning. The purpose of this study is to explore how acceptable these advance care planning discussions are and what difference they make to patients. The study will be taking place over two years.

Why have I been chosen?
You have been asked to take part because you are a patient at the Royal Free Hospital, EdenHall or University College London Hospital. We will be involving eighty participants in the study and are interested in the opinions and experiences of people of all ages and backgrounds.

Do I have to take part?
No, it is up to you to decide whether or not to take part. Your decision will not in any way affect the care that you receive. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the care that you receive.

What will happen to me if I take part?
You will be given this information sheet to take away and consider. You will also be given a consent form to sign if you decide to take part. You can return the consent form to us in the stamped addressed envelope provided. Once the research nurse receives your signed consent form, she will ask you how you feel about completing an advance care planning discussion.
**What is an advance care planning discussion?**

In an advance care planning discussion, you would meet with a trained health professional (a care planning mediator) in a place of your choice, either in your home or in the hospital. You would be given an opportunity to discuss your previous experiences of care; your current problems and concerns; your fears for the future and preferences that you may have about future care; any financial concerns you may have and the preparation of a last will. You would also be given an opportunity to complete a written advance directive. In an advance directive you can document what treatment you would not want if you were to lose the ability to make those decisions in the future. You can also appoint someone to make decisions on your behalf if you were to reach a stage where you were unable to make decisions yourself. The whole discussion would last no more than one hour and you would be given the opportunity of meeting with the care planning mediator for up to two further sessions. These discussions will be audio-taped so that our research team can examine the range and development of topics covered in the discussion and how these change with time.

The research nurse will ask you to indicate how you feel about completing an advance care planning discussion by marking your strength of preference on a simple scale. You will then be assigned to one of two groups. Those assigned to Group 1 will receive the advance care planning discussion plus usual care given by the Royal Free Hospital. Those assigned to Group 2 will not receive the advance care planning discussion, but will continue to receive the usual care given by the Royal Free Hospital. Neither you nor the researcher chooses which group you will be assigned to; it is decided on a random basis and you have an equal chance of being assigned to either of the two groups.

Whichever group you are allocated to, soon after you have given your consent to take part in this study, you will be asked to complete a number of questionnaires and a short interview with the research nurse, asking about your feelings, your level of satisfaction with your care, whether you feel able to talk openly with your doctor and family about your care and a small number of questions about advance care planning. You will be asked these questions again after six weeks.

**What are the possible disadvantages of taking part?**

If you are assigned to receive the advance care planning discussion, you will be talking in some detail about your future care and any concerns that you may have. This can be a sensitive area to discuss and some people may find it distressing to talk about these issues. Whichever group you are assigned to, you will need to complete a number of questionnaires and talk to the research nurse about your feelings, your care and some issues relating to the future. Some people may find it upsetting to talk about these things.

**What are the possible benefits of taking part?**

Patients who are given the opportunity to talk about the future and plan certain aspects of their care may find these discussions helpful. If you are not assigned to the advance care planning discussion group, there may be no immediate benefit to you. However, your participation in this research study will help us to understand better how we may develop ways of helping health care professionals discuss advance care planning with patients in the future. We hope that this will enable us to provide the very best care for people with life threatening illnesses. You may wish to raise some of your concerns about your care that this research might highlight with your usual clinical team.

**What if something goes wrong?**

If you are harmed by taking part in this research study, UCL has non-negligent (‘no-fault’) indemnity arrangements in place. If you are harmed due to someone’s negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.
Will my taking part in this study be kept confidential?
All information collected will be kept strictly confidential. The advance care planning discussion will be audio taped. You will be given a personal number that will be used when the tape is transcribed. This will ensure that your comments are anonymous. Any comments that you make to the researchers will be kept confidential. If at any time the researchers are worried about your condition, they may ask your permission to pass on their concerns to a member of the clinical team responsible for your care. With your permission, the researchers will also inform your GP of your participation in the study.

What will happen to the results of the research study?
The findings of the study will be published in medical journals and presented at academic meetings. We anticipate that the results will be available by 2009. If you would like a copy of the results, please contact Dr Louise Jones, Head of Marie Curie Palliative Care Research Unit, Department of Mental Health Sciences, Royal Free & University College Medical School, Rowland Hill Street, London NW3 2PF. Your name, identity or personal details will not be revealed in any publication.

Who is funding the research?
The research is being funded by Dimbleby Cancer Care.

Who has reviewed the research?
The study has been reviewed by the Royal Free Hospital and Medical School Local Research Ethics Committee.

Contact for further information
If you would like to discuss any details of the project further, please feel free to contact Cate Barlow, Research Fellow, Marie Curie Palliative Care Research Unit on 020 7794 0500 ext 33714.

Thank you for considering taking part in this study
Subject Information Sheet – Health Professionals

Study title
Advance care planning in advanced cancer – can it be achieved? A patient preference trial of a care planning discussion.

Invitation paragraph
You are being asked to take part in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information. If there is anything that is unclear, or if you would like some more information, please feel free to contact us. Thank you for taking the time to read this.

What is the purpose of the study?
Patients do not always feel that their preferences and wishes regarding their care are adequately considered by health care professionals. This is particularly important for those patients who are receiving specialist palliative care for potentially life-threatening illnesses. Patients vary in the amount of information they wish to receive at different stages of their illness. However, clinical experience has shown us that some patients have many fears about the future and would welcome the opportunity to discuss the options that are available to them. In particular, they may wish to discuss the future conduct of their care should a time arrive when they are no longer able to make decisions about their treatment. This is known as advance care planning.

In previous work, we developed a number of questions to help a trained care planning mediator talk with patients about advance care planning. We have already asked patients and carers for their views on the questions and are now interested in hearing the views of health professionals. We are also interested in hearing the views of health professionals on other issues to do with advance care planning.

In other arms of this study, we are exploring the acceptability and outcomes of advance care planning discussions with patients with life-threatening illnesses and the best way of measuring the effectiveness of these discussions.

Why have I been chosen?
You have been asked to take part because you are a health professional working with patients with advanced cancer at the Royal Free Hospital. As well as involving eighty patients in the patient preference randomised controlled arm of the study, we are also seeking the views of health care professionals on advance care planning.

Do I have to take part?
No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

What will happen to me if I take part?
The researcher will ask you to sign a consent form and will give you the advance care planning interview schedule to consider for one week. He/she will then arrange a time to meet with you to ask you a number of questions about advance care planning and to hear your views on the interview schedule. The interview with the researcher may take up to 30 minutes to complete.
**Will my taking part in this study be kept confidential?**
All information collected will be kept strictly confidential. The interview with the researcher will be audio taped. You will be given a personal number that will be used when the tape is transcribed. This will ensure that your comments are anonymous.

**What will happen to the results of the research study?**
The findings of the study will be published in medical journals and presented at academic meetings. We anticipate that the results will be available by 2009. If you would like a copy of the results, please contact Professor Michael King, Department of Mental Health Sciences, Royal Free & University College Medical School, Rowland Hill Street, London NW3 2PF. Your name, identity or personal details will not be revealed in any publication.

**Who is funding the research?**
The research is being funded by Dimbleby Cancer Care.

**Who has reviewed the research?**
The study has been reviewed by the Royal Free Hospital and Medical School Local Research Ethics Committee.

**Contact for further information**
If you would like to discuss any details of the project further, please feel free to contact Kelly Barnes, Research Nurse, Marie Curie Palliative Care Research Unit on 020 7794 0500 ext 38261.

Thank you for considering taking part in this study.
Appendix D: Consent Forms

Study Number:

Name of chief investigator: Dr Louise Jones

Patient Identification Number for this study:

**Patient Consent Form**

Title of project: Study to explore the planning of future care with patients with advanced illness and to determine how we may measure the effectiveness of these discussions.

Please initial box

1. [ ] I confirm that I have read and understand the information sheet dated 3rd October 2007 (version 5) for the above study and have had the opportunity to ask questions.

2. [ ] I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. [ ] I understand that you will inform my GP of my participation in the study.

4. [ ] I understand that if I am assigned to receive an advance care planning discussion, it will be audio taped.

5. [ ] I understand that relevant sections of any of my medical data collected during the study may be looked at by responsible individuals from the Marie Curie Palliative Care Research Unit, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

6. [ ] I agree to take part in the above study.

...............................................................................  ........................................  ........................................
Name of Patient  Date  Signature

...............................................................................  ........................................  ........................................
Researcher  Date  Signature
Relative/close person consent form

Title of project: Study to explore the planning of future care with patients with advanced illness and to determine how we may measure the effectiveness of these discussions.

I confirm that I have chosen to be present at the advance care planning discussion with ……………………………………………………………………….

I am aware that the discussion will be audio taped and used for the purpose of research within the Marie Curie Palliative Care Research Unit.

…………………………… ………………….. ………………………
Relative/close person Date Signature

…………………………… …………………… ………………………
Researcher Date Signature
Consent Form – Health Professionals

**Title of project:**
Advance care planning in advanced cancer – can it be achieved?
A patient preference trial of a care planning discussion.

Please initial box

1. [ ] I confirm that I have read and understand the information sheet dated 10th May 2006 (version 1) for the above study and have had the opportunity to ask questions.

2. [ ] I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. [ ] I understand that the interview with the researcher will be audio taped.

4. [ ] I agree to take part in the above study.

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Appendix E: Advance Care Planning Discussion Schedule

The care planning mediator will use the following questions as prompts in an advance care planning discussion. The questions form a guide for the care planning mediator. Not every question will be asked to each patient, but discussions will be tailored in response to the needs of the individual. The text in italics gives further information that may be used by the care planning mediator if required. The questions will not be shown to the patient.

Suggested introduction for care planning mediator

The purpose of today is to talk together about the future - any concerns you may have and any preferences/wishes that you have for your future care – things you may or may not want to happen. You may not have thought through these things before and you may not know how you feel at the moment. That’s absolutely fine.

I’m not here to give you specific advice as such, but really to encourage and help you to think through some of these issues in your own time. We have up to an hour, but we can meet up again to discuss these things further if you think you’d find that helpful.

Suggested questions for care planning mediator

A. Introductory questions

1. So firstly, just very briefly, can you tell me what the general quality of your care has been like so far?
2. And how are you feeling about the future?

B. Discussing the future with doctor(s)/nurse(s)

1. Have you felt able to talk about the future with any of your doctors or nurses? (e.g. what might happen to you, what treatment may be available, what services are available)
2. Is there a doctor or nurse who’s been looking after you who you’d like to talk to about any of these things?
3. Is there anything else that you’d like to discuss with any of your doctors or nurses?

C. Discussing the future with family and close friends

1. Have you felt able to talk about the future with your family and close friends? (e.g. what might happen to you, different treatment options, how you feel, how they feel)
2. Is there someone in your family or any of your friends who you’d like to talk to about any of these things?
3. Is there anything else that you’d like to discuss with any of your family or close friends?

D. Concerns regarding the future

1. Do you have any (other) fears or worries regarding the future?
2. Is this something that you feel able to talk about?
3. Do you have any concerns about any family members in particular? (e.g. children)
4. In thinking about the future, what do you consider to be the most important areas of your care?
5. Has anything in particular made you feel this way? (e.g. seeing relatives hospitalised/dying)
6. Do you have any financial worries or concerns? Have you thought about making financial arrangements or making a will?
7. Would you find it helpful to talk through your concerns with anyone? (Macmillan benefits line – freephone 0808 8010304; Macmillan Cancer Line – freephone 0808 808 2020)

E. Death and dying
1. Have you thought about the possibility of dying at all?
2. Is this something you feel able to talk about?
3. Has anyone talked to you about what might happen to you around the time of your death?
4. Would you like to discuss this with anyone?
5. Would you like your family or close friends to be involved in these discussions?

F. Preferred place of care
1. Has anyone talked to you about where you may like to be cared for if your condition were to deteriorate?
2. Is this something that you’d like to talk about or not? (See text box below)

Preferred place of care (for use if required)
Some people will want to be cared for at home, others may prefer to be cared for in a hospital or a nursing home. Others may prefer to be cared for in a hospice, places which specialise in the care of people with chronic illnesses. It won’t always be possible to meet each person’s wishes, but if your doctors and nurses know what your preferences are, then they can do their best to meet those preferences.

3. Is there anything that is particularly important to you in thinking about where you may like to be cared for?
4. Where do you think your first choice would be? And your second choice?
5. Would you like an opportunity to discuss this with anyone or to make your wishes known to anyone in particular?

G. Identifying coping mechanisms
1. As you know, being unwell can be a serious challenge in life. Is there someone or something that sustains you when you face serious challenges in life?
2. Do you have any spiritual or religious beliefs that have helped you deal with difficult times?
3. Is there anyone else that you’d like to talk to about anything we’ve discussed today?
H. Future health care decisions

1. Have you been able to talk to any of your doctors or nurses about what you would or wouldn’t want to happen if your condition were to deteriorate - what treatment you would or wouldn’t want to receive?

2. If you become very unwell and unable to make decisions, how would you feel about the doctors and nurses looking after you, making decisions about your care and treatment?

3. Would you feel confident in those doctors and nurses making those decisions on your behalf?

4. Would you like the medical staff to continue measures to keep you alive at any cost?

5. If your heart stopped beating and you stopped breathing, do you have any views about whether you want the doctors and nurses to try and bring you back to life, that is to resuscitate you?

6. How would you feel about your family or those you are close to making decisions for you if your condition were to deteriorate?

7. Have you been able to talk to your family and close friends about what you would or wouldn’t want to happen if your health were to deteriorate - what treatment you would or wouldn’t want to receive?

8. Sometimes people want to document their wishes and preferences regarding future health care decisions, so that if their condition were to deteriorate they have already communicated their preferences. Is this something that you would like to know more about? *(See text box below)*

9. Do you think you would find it helpful to make your preferences known using any one of these documents?

**Documenting future health care decisions (for use if required)**

Your preferences regarding future health care decisions can be documented in a number of ways:

- **Firstly, through a statement of wishes and preferences**, where a record is made - usually in your medical notes - of your wishes and preferences for future treatment or care. It may also state your feelings and the values that govern how you make decisions in life. They are not legally binding but they can provide health professionals with information to help them make decisions in your best interests if you were no longer able to make those decisions yourself.

- **Secondly, through making an advance decision.** This used to be known as a living will or an advance directive. It is a document where you specify what specific treatments you wouldn’t want to receive in particular circumstances. It only comes into effect if you were to become too ill to make those decisions in the future. From April 2007, these documents will be legally binding.

- **And lastly, you can nominate someone to make decisions for you if you were to become too ill to make those decisions in the future.** This is known as a *last power of attorney*. 
If the patient wishes to make an advance decision or appoint a lasting power of attorney, Terrence Higgins Trust documents will be used. The care planning mediator should discuss where the patient wishes to keep the completed document and whether they wish to make it available to the clinical team.

J. Further discussions

1. Is there anything else that you’d like to discuss regarding the future - anything else that’s on your mind that we haven't talked about today?
2. We’ve talked about some quite sensitive issues today. How are you feeling right now?
3. Would you like to arrange another meeting? (Maximum 3 sessions in total)

There will be some informal closure at the end of the discussion. If the patient needs further support, the care planning mediator will encourage the patient to contact their clinical team.
Appendix F: Views of the care planning mediator on relatives being present during the discussion

One or more members of the patient’s family were present during six (12%) of the discussions.

Table showing when relatives were present

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<thead>
<tr>
<th>Patient</th>
<th>Discussion 1</th>
<th>Discussion 2</th>
<th>Discussion 3</th>
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<tbody>
<tr>
<td>M3</td>
<td>-</td>
<td>Relative present</td>
<td>Relative present</td>
</tr>
<tr>
<td>M6</td>
<td>-</td>
<td>Relative present</td>
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</tr>
<tr>
<td>M26</td>
<td>-</td>
<td>Relative present</td>
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<tr>
<td>M49</td>
<td>Relative present</td>
<td>-</td>
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</tr>
<tr>
<td>M51</td>
<td>-</td>
<td>Relative present</td>
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In three instances (M3,M6,M49), the relatives had wanted to be present at the first discussion but it was decided that this may detract from the main focus of the discussion and hence, the study team agreed that relatives could only be present during the second or third discussion.

In the one instance where a relative was present during the first discussion, she had come into the room partway through the discussion and the care planning mediator didn’t feel it appropriate to ask her to leave. However, she did say after the discussion that having the relative present appeared to affect how the patient responded to the questions and caused him to become uneasy.

In three instances (M3,M26, M51), the patients had requested that their relatives be present during the second discussion so that they could share information and discuss specific aspects of advance care planning together. M3 had said that he wanted his wife and son involved in the decision-making process regarding making a living will. During the discussion, they completed the Lasting Power of Attorney document together.

In two instances (M3,M6), the care planning mediator felt that having relatives present meant that the discussion was a lot less focused on the patient/advance care planning and more focused on the current needs of the relatives. In two instances (M26,M5), the care planning mediator felt that the relatives contributed to the discussion and did not take the focus away from the patient or dominate the conversation.

In two instances (M3,M6), the relatives were at a different stage than the patient regarding coming to terms with the patient’s diagnosis/prognosis. In both cases, this meant that the care planning mediator felt unable to follow-up particular comments that the patient made in a way she would have been able to if the relatives hadn’t been present.
# Appendix G: Summary of Main Themes from ACP discussions

**40 participants included; 52 ACP discussions in total**

29 patients had 1 session; 10 patients had 2 sessions; 1 patient had 3 sessions

Relative(s) present at session 1 (1 participant); session 2 (4 participants); session 3 (1 participant).

<table>
<thead>
<tr>
<th>Topic</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>A. Feelings about the future</strong> - Asked patients how they felt about the future.</td>
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</table>
| **General feelings about the future** | • Feels good about the future (15,19,23,32,35,52).  
• Doesn’t know how s/he feels about the future (11,20,21,29).  
• Finds uncertainty about the future hard to deal with - stressful (9,21,28,33,37,43,51,60).  
• Doesn’t think about the future (2,10,20,34,35,40,57,60). No point in worrying about the unknown (2,34,40,57).  
• Doesn’t want to think about the future (4,6,11,18,29,45,49). |
| **Trying to be positive but has thoughts about possible deterioration in health** | • Thoughts in the back of mind about possible deterioration in health (3,5,6,9,11,15,16,20,21,23,24,26,27,28,32,34,35,37, 38,39,40,45,47,49,51,52,57,60,61) but trying to be positive and not thinking about that (3,5,6,9,11,16,20,21,23,24,26,27,28,32,34, 35,37,38,39,40,45,47,49,51,52,57,60,61).  
• “You have got to be positive as well, so I don’t sort of dwell on it. I probably did when it was first confirmed that I had cancer, that’s when your mind’s racing and fears for the future, future of the family. But when things start getting a bit better with treatment, you push them aside and start thinking positively with things you want to do.” **M60, session 1**  
• Wants to be positive as believes attitude affects health (5,16,21,32,33,38,45,49).  
• “In my more maudlin moments....I sit there and go through my funeral.... I also know that if I dwell on it, I’ll go right down and....I don’t want to do that. I have to live from day-to-day, and I have to find a way of managing it.” **M16, session 1**  
• “I’m quite positive about it.... You don’t want to think in a negative way.....You don’t want to be talking about things like that....because that makes you worse than what you are.” **M49, session 1**  
• Focusing on treatment options that might prolong life expectancy (3,16,32,33,35,51).  
• “I’m just concentrating really on, on taking the...treatment medication....keeping myself positive really....that’s my way of doing it. I do believe in mind over matter to a fair extent.” **M32, session 1** |
<table>
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<tr>
<th><strong>Hope</strong></th>
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| • Has hope for the future (5,15,16,19,21,23,24,27,33,35,38,39,40,47,51). Feels hopeful about treatments (15,16,21,32,33,35,51).  
• Disappointed/sad that plans have had to change (26,28,32,45,47). Rethinking hopes/expectations for the future (26,28,32,45).  
• “It’s this notion of realistic hope, isn’t it? I mean, I’m not stupid, I know that my life is going to be shortened, but I also know that people in my position can go on for years.” **M16, session 1** |
| **Taking it one day at a time** |
| • Taking it one day at a time, enjoying each day and not thinking too far ahead (6,10,16,18,20,21,23,26,27,28,30,32,33,34,37,40,45,47,49).  
• “In my more maudlin moments, of course, you know, I sit there and go through my funeral.... I also know that if I dwell on it, I’ll go right down and....I don’t want to do that. I have to live from day-to-day, and I have to find a way of managing it.” **M16, session 1** |
| **Wants to get on with living a normal life** |
| • Wanting to get on with life as normal (6,9,10,11,20,21,23,24,26,37,38,39,40,47,49,52,57,60).  
• “It’s simply that I need to....continue with a life as well as we can, as normally as we can, for as long as we can.” **M26, session 1**  
• Wants to give hope to those around him by carrying on as normal (39).  
• “I just think positive.....don’t give it a thought, I just want to get on with life.” **M57, session 1** |
| **Planning ahead for when health deteriorates** |
| • Already making some plans for when his/her health deteriorates (15,16,23,24,38,52).  
• Not sure how to balance planning for her deterioration with maintaining a positive spirit (38,39). Wants to acknowledge reality of situation without surrendering to it (39).  
• “Acknowledging some of the realities…without sort of, uh, surrendering to them….is part of the problem.” **M39, session 2** |
| **Planning other aspects of life** |
| • Making plans for enjoying the rest of his/her life – doing things s/he wants to do (16,26,27,32,33,34,37,38,40,47,51,57,60).  
• Not making as many long term plans now (18,23,24,37,38,51).  
• “You can’t have long term plans. You can’t think of next year... I never think of next year now. I think of now.” **M23, session 1**  
• Not sure how s/he’ll be feeling so finds it hard not being able to make long term plans (18,28,37,38,45,51). |
| **Specific concerns about the future** |
| • Concerned about process of deterioration and symptoms (2,4,24,27,28,34,37,38,39,40,43,45,49,51,60,61) - pain in particular (2,4,27,34,43,45,49,51,60,61).  
• “If it got worse, what’s my main fear? Pain. I’m a chicken.” **M60, session 1**  
• Has fears/concerns about death/dying (2,4,11,15,24,27,28,37,38,39,40,47,49,60,61).  
• Concerns about the future relate to family members (2,5,15,16,18,21,24,26,27,33,34,37,39,40,45,47,52,61). Concerned about how his/her family will cope (2,5,18,26,27,34,37,39,45,47,52,61).  
• In talking about her parents, said “They’re the ones I worry about, how
they’ll cope.” M52, session 1

- Concerned about being a burden/becoming physically dependent on people as s/he deteriorates (15,16,18,34,40).
- Has financial concerns regarding the future (33,39,43,49).
- Has concerns about where s/he would be cared for – PPC (20,23,31,45,61).

B. Communication with health professionals - Asked whether s/he had been able to talk to health professionals about the future: whether there was anything s/he wanted to speak to them about that s/he hadn’t yet been able to talk about.

Talking to doctors about the future

- Hasn’t talked extensively to doctors about the future/possible deterioration in health (1,2,3,4,5,6,9,10,11,15,16,18,19,20,21,23,24,26,27,28,29,30,31,32,33,34,35,37,39,40,43,45,49,51,52,57,60,61).
- Hasn’t talked to doctors about dying process (2,19,20,21,24,26,29,30,32,33,35,37,43,51,52,60) or prognosis (9,18,24,31,32,45). Has talked to doctors/nurses about dying process (1,15,28,61).
- Has spoken to CNS about the future (15,31,33,35). More comfortable talking to CNS/palliative care nurse than doctors (2,5,35).
- Doesn’t want to talk to health professionals about the future at the moment (11,18,20,21,23,24,26,27,29,30,33,39,40,49,51,57).
- Doesn’t want to talk about dying process at the moment (18,19,20,21,24,26,29,33,39,43,51). Doesn’t want to ask directly about prognosis (9,18,40,49).
- In talking about discussing death with the health professionals, said “I think if, if I, if I understood what uh, possibly happen to me, I think I could, I think I would cope with it ok, but uh, I, I don’t know whether I’m ready to want to understand that at this present moment.” M26, session 1

Timing of this kind of conversation is important

- Too soon to have conversations at the moment but recognised there is a time for these kinds of conversations (1,6,11,18,21,23,24,26,27,33,40,49,51,57).
- “One knows the support is there so that when, when one feels the time’s right to ask particular questions, you know the answers will be there....which is very reassuring.” M26, session 1
- “If for instance Dr Davis said to me, ‘Look, it’s, it’s flaring up again’.... And if it was, then I think I’d say, ‘Well now, let’s plan.’” M23, session 1
- Doesn’t want to think too far ahead as too much information about the future will overload her/him (15,18,24,27,33,51).

Different aspects of communication with doctors

Being given information

- Doctors are reluctant to give information regarding the future (1,3,4,5,10,16,19,33,34,43,45,51,60,61).
- “They always try to be positive.... He’s always trying to be upbeat, the consultant. So he’s not going to stop me to say ‘what happens if it goes wrong?’ He doesn’t want to discuss it.” M33, session 1
- Wants more information from doctors about the future
what s/he can realistically expect for the future (3,4,5,9,16,24,39,61), prognosis (3,5,19,34,35,39,43), what process of deterioration will look like (34,39,52,60,61), the dying process (1,37,52,60), if things weren’t looking good (3,5,9,24,35,43).

- Wants information given to her/him as doesn’t know what to ask for (1,3,4,5,19,43).
- “The biggest problem about getting care is knowing the right questions to ask.... If I’d known, if I’d thought to ask....I could have asked, but I didn’t know to ask.....That’s what I think you need as a patient .... I need gratuitous information.” M43, session 1
- Taking the lead from health professionals on when to have conversations about the future (16,23,26,32,35,43).
- “There also needs to be a kind of a gentle nudging…. People...in my position, need the help… Support.... needs to be there.....so that....not only can you ask but you’re, I don’t know, prompted in a good way. “ M26, session 1
- Needs information whilst s/he has time to make decisions/plan (1,3,4,5,10,34,37,39,43,51,52).
- “Hopefully they can manage to give me answers....Saying ‘that’s what you have and that’s what you can do about it, or that’s what you can’t do about it’. That would be more important than just letting me....just carry on like this.” M9, session 2
- Doesn’t know prognosis (3,4,5,9,10,18,24,31,33,37,40,47,49,51). Wants to know prognosis so that s/he can plan (3,5,34,39,43). When s/he asked doctors about prognosis, said they couldn’t tell him/her (3,4,5,10,33,34,37), they told him/her roughly (11,34,38,39,43,47,60).
- Able to ask CNS/palliative care nurse anything and gets information from them (2,4,6,9,15,18,19,23,26,27,28,29,31,33,34,35,43).
- Would feel comfortable asking his/her doctors questions about the future (26,29,30,34,37,40,43,47,51,52,57).

Lack of time in clinic appointments
- There is a lack of time in clinic appointments to talk about the future (4,5,9,10,19,20,28,34,38,40,45,60,61).
- “The doctors to be fair are very busy, so I don’t really want to take up too much of their time, so I have not talked to them because it is probably quite a lengthy subject.” M60, session 1 (talking about what might happen as his condition deteriorates)
- “They are so busy, they never have to time to sit and talk about those things with you (talking about the future).” M9, session 1

Poor continuity of care
- Hasn’t seen the same doctor each time and has found this hard (31,33,4,61). Wants continuity of care (28,31,33,37,43,45,61).
- There should be a specific person who is a contact point and is responsible for giving information to patients at each clinic visit (1,3,4,45,61).
- “I think at times it would be nice having a link person ….because I think you tend to get lost up there.” M45, session 1
**Things that help him/her in clinic appointment**

- Writes down questions before app’t which helps him/her remember what to ask (1,4,18,39,43,45).
- Family come to consultations/ask questions (5,18,30,35,37,49,51). They think of things s/he doesn’t think of (30,35,37,49,51).

**Talking to health professionals after ACP discussion**

- After session 1, planned to talk to doctors/nurses about the future (1,6,10,16,26,35,37,38,39,43,45,51,60,61) – ask about prognosis (5,19,35,39), likely course of deterioration (37), making future health care decisions (26,37,45), PPC (1,2,10,31), getting referral to a CNS/hospice (38).
- Got good news at clinic appointment after session 1 so didn’t ask questions s/he had intended to ask (1,6,51).

**C. Communication with family/close friends** - Asked patients whether they had been able to talk to their family/close friends about the future; whether there was anything that they wanted to speak to them about that they hadn’t yet been able to talk about.

**Talking to family**

- Has talked to family about illness/treatment (1,2,3,4,5,9,11,15,16,18,19,23,24,26,27,28,30,31,32,33,34,35,37,38,39,43,45,47,51,52,57,60,61). Talks to friends about cancer (2,3,11,15,19,20,23,24,28,31,32,35,38,40,45,57,61).

**Has talked to family/friends about the future**

- Has talked openly with family about the future - 2,30,31,33
- Has only talked a little about the future, certain things not yet discussed – 3,9,16,18,19,21,24,26,27,28,32,34,35,37,38,39,43,45,49,51,52,60,61
- Feels fine talking to family about the future (2,30,31,35,37,43,52).
- Talks more to certain family members about the future than to others (2,11,16,18,24,32,35,38).
- Feels like family know his/her wishes for the future re. burial/funeral/will (27,31,37,38,45,51,61).
- Feels like family know wishes re.making future health care decisions (19,30,34).

**Hasn’t talked to family about the future**

- Hasn’t talked to family about future (5,10,15,47,57).
- Certain things not discussed with family (1,11,15,18,19,26,45,52).

**Wants to talk to family/friends about the future**

- Wants to talk to family about certain things to do with the future (3,10,15,18,19,26,27,30,39,60) – future health care decisions (3,10,15,26,30).
- Wants to best prepare his partner, but without being too pessimistic (39).
- “It’s trying to find the balance.... You have to try and plan for the worst case without unnecessarily upsetting or disturbing uh, those who are dependent on you...It’s uh, trying, giving them and yourself you know, hope...by sort of, carrying on...as if there isn’t any real problem....But at the same time ... adding the plans so that ....they are well catered for.” M39, session 1

**Doesn’t want to talk to family/friends about future at the moment**
<table>
<thead>
<tr>
<th>Why s/he doesn’t want to talk to family/friends about the future at the moment</th>
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<tbody>
<tr>
<td>• Doesn’t want to talk to family about the future at the moment (1,2,4,5,6,9,11,16,20,21,23,28,29,34,35,37,38,40,43,45,47,49,52,57).</td>
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<tr>
<td>• Doesn’t want to talk about cancer too much with friends (9,26,28,33,38,40,45,49).</td>
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**Difficulties with certain family members**

<table>
<thead>
<tr>
<th>Communication difficulties with relative/s concerning her/his illness (6,15,16,18,24,27,28,32,34,38,39,45,47,49,61).</th>
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<tbody>
<tr>
<td>Relative/s are in denial about his/her illness (6,15,16,18,24,27,28,32,34,38,39,45,47,49,61).</td>
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<tr>
<td>“My partner... is very much in denial, you know. She doesn’t want to confront you know, the likelihood that I’ve uh, I’ve probably only got 2 or 3 years... Trying to persuade her to make the necessary adjustments in time... and help her do those.” M39, session 1</td>
</tr>
<tr>
<td>Relative/s doesn’t want to talk about her/his illness/the future (16,18,24,32,34,38,39,45).</td>
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</tbody>
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**Effect of ACP discussion on communication with family**

<table>
<thead>
<tr>
<th>Decided in ACP discussion to get additional help for family communication difficulties (6,18,27,39).</th>
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<tbody>
<tr>
<td>Talked to his/her partner about the future after session 1 (3,19,26,39,51) – living will (3,26,51); PPC (26); wishes re. blood transfusions/resuscitation (19); prognosis (39).</td>
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<tr>
<td>Wife and husband communicated talked about things during 2nd session that they hadn’t communicated about before (3,51).</td>
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</table>
### D. Finances -

Asked patients whether they had financial concerns/worries; whether they had made a will. Where appropriate, gave patients Macmillan Benefits line.

| Writing a will | • Has made a will (1,2,3,4,5,9,10,19,24,27,31,33,34,35,37,45,51,52,61). In process of making a will (32,38).  
• Hasn’t made a will (6,11,16,43,49,57).  
• Plans to make a will or make changes to a current will (6,11,20,27,37,51,52).  
• Not discussed (15,18,21,23,26,28,30,39,40,47,60). |
| Benefits | • Receiving benefits (2,6,9,16,49). Wasn’t aware of benefits s/he is entitled to (1,4,26,35,37).  
• ACP mediator gave him/her contact details for benefits line (1,4,10,37). Plans to talk to someone about benefits (1,4,10,35,37). |
| Financial worries | • No financial worries at the moment (2,4,5,6,9,10,11,16,20,21,26,27,30,31,32,33,34,35,38,45,57,60).  
• Has financial worries (3,28,37,39,40,43,49).  
• Not discussed (15,18,19,23,61). |
| Has been sorting out finances/making a will | • Has been sorting out finances recently (26,31,32,34,38,39,43,45). In process of making a will (32,38). |
| Changes after ACP discussion | • Made contact with social worker/Macmillan benefits line in between sessions 1 and 2 (1,26). |

### E. Death and dying -

Where it felt appropriate, asked patients if they had thought about death/dying and whether this is something they wanted to talk about.

| Thinking about death | Sometimes thinks about death  
• Sometimes thinks about death/dying (15,16,19,20,21,24,30,33,35,37,38,40,45,47,52,60,61).  
• Death has become more of a reality (15,23,28,51,52,61).  
• “Statistically I’m more likely to die than other people I know. But actually.....the reality is that we are all going to die....I think the difficult thing..with cancer is that you’re living with it, I’m living with it as a much closer reality.” M28, session 1  
• Accepts that s/he will die/ready to die (2,19,30,31,43,52). We’ll all die someday (18,19,23,27,28,32,34,43,47,49,51,60).  
• Spiritual beliefs help her/him cope with the idea of death and dying (3,23,31,32,34).  
• Has ideas of the ideal way s/he would like to die (2,3,32,38,43,49). |
| Not thinking about death | • Doesn’t want to think about death/dying (5,6,10,11,16,20,21,24,29,32,33,34,35,40,45,51,57,60).  
• When/if s/he deteriorates it will feel more appropriate to think/talk about |
| Death/dying | death/dying (5,21,24,32,33,34,35,40,51,57).  
• Doesn’t feel s/he’s come to terms with the fact s/he’s going to die (26,28,35,38). |
|---|---|
| Fears | Has fears/concerns about death/dying (2,4,11,15,24,27,28,37,38,39,40,47,49,60,61).  
• Concerned about process of deterioration and symptoms (2,4,24,27,28,34,37,38,39,40,43,45,49,51,60,61) - pain in particular (2,4,27,34,39,43,45,49,51,60,61).  
• Has had some negative experiences seeing others dying which have affected him/her (2,3,4,11,24,37,49,60). Has had experiences seeing others dying which have been positive (26,28,51).  

| Discussing with health professionals | Hasn’t talked to doctors about dying process (2,19,20,21,24,26,29,30,32,33,35,37,43,51,52,60) or prognosis (9,18,24,31,32,45).  
• Has talked to doctors/nurses about dying process (1,15,28,61).  
• Wants to talk to health professionals more about dying process (1,37,52,60).  
• In talking about discussing death with the health professionals, said “If I understood what uh, (may) possibly happen to me...I think I would cope with it ok, but...I don’t know whether I’m ready to want to understand that at this present moment.” M26, session 1  

| Discussing with family/close friends | Has talked to family about certain things to do with death (2,9,27,28,30,31,35,37,45,52,61) - funeral/burial wishes (2,9,27,28,31,37,45,61), wishes regarding resuscitation (30).  
• Hasn’t talked to family about death (18,20,26). But spoke to wife about PPC after session 1 (26). Wants to talk more to family about death in the right time (18,40,43).  
• Doesn’t want to talk to family/friends about dying at the moment (9,20,23,40,43).  

| Euthanasia | Thinks euthanasia is a good idea (2,9,35,49). May be an option for him/her (9,35,49).  
• Euthanasia wouldn’t be an option for him/her (3,19,23,31,45).  

| Funeral | Has thought about funeral (16,19,20,23,38,40,43,45,61) and made plans for funeral (20,23,38,40,43,45,61).  
• Hasn’t thought about funeral (32).  

| F. Preferred place of care | F. Preferred place of care - Where appropriate, asked patients whether they had thought about where they would want to be cared for if their health deteriorated. Explained options available (hospice; home care with nursing support [i.e. Marie Curie nurses]; nursing home; hospital). Said it wasn’t always possible to be cared for in the place of their choice but encouraged patients to talk to health professionals to make their wishes clear.  

| Thoughts about PPC | Doesn’t want to think about PPC yet (4,16,30,33,39,40).  
• When asked about PPC, said “I will think about that...when the
circumstances arise... If you don’t mind me saying so, the questions really are very premature right this very minute...there’s a long way to go yet in this life.” **M4, session 2**
- Has concerns about where s/he would be cared for – PPC (20,31,45,61).
- Her/his decision would depend on circumstances at the time (1,4,6,20,26,29,34,45).

**Hadn’t realised what the options were**
- Hadn’t thought about PPC before (4,6,15,18,29,30,33,34,52,60).
- Hadn’t realised what was available in community – home/hospice (1,2,4,10,15,16,18,20,21,31,34,35,37,38,40,45,49,51,52,60,61).
- Mediator informed him/her what was available (1,2,4,5,6,9,10,11,15,16,18,19,21,31,33,34,35,37,38,39,40,45,49,51,52,60,61).
- Indicated that s/he found this information helpful (1,2,4,15,18,31,34,35,37,38,40,45,52,61).
- “I think it’s been very useful...to hear about Macmillan and Marie Curie and the local hospice, and actually feel, ‘well, that’s something that I can investigate at some point’. There’s a bit of me that thinks, ‘I don’t want to think about this. I don’t want to think about dying when I’m feeling well, and living a good life’.... But, you know, we are all going to die... It’s also, in some respects, a kind of privilege to be ...given....advanced warning of it....Even if you don’t know when it’s going to happen...that you actually think about those things.....It’s not easy to talk about these things at all, but...all information is power.” **M40, session 1**

**Concern about being a burden on family**
- PPC decision affected by concern about being a burden on family/friends (2,3,5,15,18,26,29,31,34,35,37,38,39,40,45,49,51,60,61).
- Would prefer to be at home, but concerned about burden on family/friends (2,3,15,18,29,31,35,38,40,49,51,60,61).
- “I think being cared for at home in the beginning is a good thing, but you put lots of pressure on people if you do that. So I probably would like to be at home for as long as I could.” **M15, session 1**

**Choices for PPC**

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Hospitality would be first choice (2,5,24,31,37,40,45,51) but some of these indicated that they hadn’t known what was available to enable them to stay at home/second choice (3,15,20,32,35,43).</th>
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<tbody>
<tr>
<td></td>
<td>Wouldn’t want to die in a hospice (49,60).</td>
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<tr>
<td></td>
<td>Seeing someone die in a hospice was a positive experience (2,10,37,43,45,51)/negative experience (11,49).</td>
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<table>
<thead>
<tr>
<th>Home</th>
<th>Wants to stay at home as long as possible (3,4,10,11,15,16,18,19,20,21,23,28,29,30,31,32,33,35,38,43,45,47,49,51,57,52,60,61).</th>
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<tbody>
<tr>
<td></td>
<td>Wants control over his/her quality of life (3,51,52,19). Home is familiar (51,52). Relaxed (3).</td>
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</tbody>
</table>
Knows of someone who was cared for at home - was a positive experience (10,26,40)/ negative experience (28,45,49). Poor package of care (45).

Hospital/nursing home/going overseas
- Wouldn’t want to be in a hospital (2,3,6,16,21,31,51). Had bad experiences in hospital (2,4,51), impersonal, lack of privacy/freedom (3,6,51).
- Knows someone who had a negative experience dying in a hospital – pain (2,3). Seen distressing sights in the hospital (4).
- Nursing home would be first choice (34)/second choice (29,37). Always assumed she’d go into a nursing home (20).
- Would consider going overseas (3,9,43)

Talking to family about PPC wishes
- Hasn’t talked to family about wishes for PPC (3,16,21,47).
- Plans to speak to his wife about being at home after session 1 (60). Talked to wife about PPC after session 1 (3,26). His first choice changed as a result of her wishes (3).

Talking to doctors about PPC
- Wants to talk to doctor/CNS/Macmillan nurse about PPC after ACP discussion (1,2,10,31).
- Thinks doctors wouldn’t want to talk about PPC (10).
- *Re. talking to HCPs about PPC, said, “I’ve not enquired about that, because as nice as people are, a lot of them would say ‘well wait till it happens’...So even the professionals, you know, there’s quite a few people who say, you know, ‘you’re alright at the moment, why don’t you wait till it happens’.”* M10, session 2

Changes after ACP discussion
- Wants to talk to doctor/CNS/Macmillan nurse about PPC after ACP discussion (1,2,10,31).
- Talked to wife about PPC after session 1 (3,26). His first choice changed as a result of her wishes (3).
- In first session said – “I probably would want to die in a hospice as opposed to home because I think your home should be a place where there are fond memories, not memories of death.” M3, session 1. And then in second session, when his wife was present, she said that she would want to care for him at home. He responded by saying ‘I don’t mind that...as long as it’s not too much of a drain on [son] and [wife], but I think...if it becomes too much of a chore....maybe there’d come a time where I’d have to go to Marie Curie or somewhere like that....you know, like, if I become doubly incontinent.” M3, session 2. This showed clearly how the patient’s choice is very much determined by what they feel those close to them can handle.
- After session 1, will get a referral to the hospice to access day care (38).

G. Identifying coping mechanisms - Asked patients how they usually cope with difficult situations, any coping mechanisms or things that help them. Asked whether they had spiritual or religious beliefs.
### Spiritual/religious beliefs
- No spiritual/religious beliefs (1,4,5,6,9,11,19,21,30,33,43,45,47,57). Is spiritual but not religious (2,18,24,28,32,37,38,40,52,61). Is religious (10,23,31,34).
- Has spiritual or religious beliefs that help him/her (3,10,23,27,31,32,34,38,60,61).
- Was brought up religious but not practising (16,20,29,35,37,39,49,51,52). Not something that sustains her/him (16,20,29,49,51).

### People
- Find it helpful to talk to people about what’s going on (1,15,16,19,21,23,24,26,30,33,34,35,37,38,39,40,43,52,57,61).
- Talks to those in a similar situation (with cancer) who understand what it’s like (16,19,24,26,37,38,40).
- Cancer support group (16,38,39,45,61).
- Friends (15,16,19,21,23,24,33,38,40,43,60,61)
- Family (21,24,26,30,31,34,35,37,38,40,52,57)

### Mental attitude
- Having the right mental attitude (2,3,4,6,11,18,20,21,24,26,27,32,33,34,35,37,38,39,40,43,47,49,52,57,60,61).
- Being positive (21,26,32,35,38,39,40,49,57,60,61).
- Copes by getting on with life as normal (9,11,21,24,26,27,33,40,49,57). Working (9,15,33,39,47,49,57).

### Other
- Complementary therapies (4,5,10,11,16,24,28,31,38,40,61) - Massage (4,5,10,31); Hydrotherapy (5); Healing (5,16,40); Homeopathy (11,40); Reflexology (40,61); Yoga (24,61); Pilates (61); Hypnotherapy (28); Meditation (28,38,61); Dietary changes (38,40); Acupuncture (40).
- Getting outdoors (4,6,20,23,24,26,30,32,34,37,49,51,60,61).
- Physical exercise (4,10,11,16,19,24,26,28,32,34,37,51,61).
- Working makes him/her feel there is some normality (6,9,39,49,57).
- Support from the hospice (5,16,23,24,28,31)
- Being given information (16,18,19,24,26,28,35,38,39,40,45,51,61).
- Having a sense of control through having information (1,28,35,38).
- Sees therapist/counsellor/coach (15,24,28,32,40).
- Going away (10,30,32,34,37,38,43,51,61).

### H. Future health care decisions
- Explained about living will and that some people like to make their wishes/preferences clear in case they are unable to make decisions in the future. Explained AD, LPA and Statement of Preferences and Wishes. Asked for views on resuscitation. Where appropriate explained that they could change their minds and that the AD wouldn’t come into force unless they are unable to make decisions. Where appropriate encouraged patients to talk to doctors about their decisions and encouraged them to give a copy to doctors to keep in medical notes. Asked whether they would trust medical profession to make decisions on their behalf.

### Talking to doctors about making future health care
- Hasn’t talked to doctors about preferences for future health care decisions (1,9,16,20,21,23,26,28,30,31,33,35,43,45,47,49,51,61).
- Doesn’t want to speak to doctors about it at the moment but if her/his condition were to deteriorate s/he would talk more to doctors about
<table>
<thead>
<tr>
<th>decisions</th>
<th>preferences for future care (23,30,33,43,47,61).</th>
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<tbody>
<tr>
<td>• “I wouldn’t want to do it now….Because at the moment I’m trying to plan for success rather than failure….But if failure becomes a likely option then I’ll switch to a different mode.”</td>
<td>M33, session 1</td>
</tr>
<tr>
<td>• Wants to talk to doctors about future health care decisions (26,28,37,45) but there isn’t time in clinic appointments (28,45).</td>
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<tr>
<td>• “But there’s not really time to have that conversation, when would you have it – in the clinic, when you’ve got people waiting outside?”</td>
<td>M28, session 1</td>
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<thead>
<tr>
<th>Trusting medical profession to make decisions</th>
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<tbody>
<tr>
<td>• Trusts nurses and doctors to make the best decisions on his/her behalf (2,6,9,10,11,18,20,21,23,26,27,28,29,31,32,33,34,35,37,38,39,40,45,49,51,60).</td>
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<tr>
<td>• “You just have to trust them…trust the medics to make the right decisions and um, we know that sometimes they do that and sometimes they don’t….But um, um, there’s no point in getting stressed out about it.”</td>
<td>M34, session 1</td>
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<tr>
<td>• But feels future health care decisions should be made in conjunction with her family/friends (21,23,26,27,28,29,33,40,49,60).</td>
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<td>• “I guess in general I have confidence in the health service….If there was a genuine uncertainty and they couldn’t make up their mind what was best, and they wanted someone to pin the blame on if they get it wrong, then I guess they could ask members of the family.”</td>
<td>M33, session 1</td>
</tr>
<tr>
<td>• “If there was a decision to be made and there wasn’t a, there was a choice and the doctors really didn’t know which was best, and it was a toss up….And it’s not necessarily that they wouldn’t know which is best… If they’re making a decision in your best interests, that interest may well be served by…having your family involved in the discussions.”</td>
<td>M33, session 1</td>
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<tr>
<td>• Doesn’t trust doctors to make the right decisions (3,5,24).</td>
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<tr>
<td>• “I think doctors are always on the side of preserving life, sometimes they are stupid about it. So I wouldn’t (trust them) because they’d probably decide to keep me alive when I shouldn’t be kept alive.”</td>
<td>M24, session 1</td>
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<tr>
<td>• Doesn’t know if s/he would trust the doctors to make decision in his/her best interests (43,52,57).</td>
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<tr>
<th>Quality of life more important than length of life</th>
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<tr>
<td>• In thinking about being kept alive, quality of life is more important to him/her than length of life. Wouldn’t want to be kept alive at all costs if quality poor (6,9,21,23,26,28,31,32,33,35,37,43,45,49,51,57).</td>
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<tr>
<td>• “The purpose of medicine is to alleviate suffering…Um, it’s not about extending your life at any costs….There’s got to be quality of life.”</td>
<td>M32, session 1</td>
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<tr>
<td>• If s/he was dying, would want to go peacefully/with dignity (28,31,32,43,45).</td>
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<td>• “Give me a graceful exit if you can and make it, not quick, but….you know, don’t prolong it just for the sake of it.”</td>
<td>M43, session 1</td>
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<tr>
<th>Advance directive/ statement of wishes and</th>
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<tbody>
<tr>
<td>• Didn’t know what advance directives were (4,6,10,27,51,57). Appreciates information about living will (1,4,9,15,18,19,21,26).</td>
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<td>• Hadn’t thought about documenting his/her preferences before (19,24,35,37,39,57,61).</td>
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<tr>
<td>preferences</td>
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<td>• His/her decisions about future treatments would depend a little on how things work out at the time (20,23,24,26,34,39,43).</td>
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<td>• Hard to say what you would want when you’re well as you have no idea what you will feel like (23,39).</td>
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<tr>
<td>• <em>Regarding making a statement of wishes and preferences, said.</em> “Those kinds of things, it’s hard to make them when you’re well…..because you’ve no idea what it feels like to be so weak….The difficulty is that when you’re feeling very well…and you’re feeling full of life….it’s hard to say ‘oh, yes, now when I die I would like this and that’.” M23, session 1</td>
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<tr>
<td>• Wouldn’t know what treatment options would be available for making an advance decisions (26,28,33,35,39,40,45,61) Would want a list of treatments she may be offered if her health deteriorated (28,39,40).</td>
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<td>• “It’s a bit easier to write a birth plan than to write or plan on something when I’ve got no idea what the options are….or what the problems will be.” M33, session 1</td>
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<tr>
<td>• Wouldn’t want to make a living will (20,27,29,38,57).</td>
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<tr>
<td>• Wants to make an advance directive (2,3,5,6,9,10,11,15,19,21,26,31,37,45). But would want to talk to family first and involve them in it (3,10,11,15,26,52).</td>
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<tr>
<td>• Not sure if s/he wants to make an advance directive yet (1,4,18,24,35,52).</td>
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<tr>
<td>• Will deal with this when s/he deteriorates/when it feels more appropriate (4,15,24,33,35,43,61).</td>
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<tr>
<td>• “When you start touching on that stuff, you know, like will you want the ventilation switched on or off or whatever, then it is tough for me, because I am not used to thinking about that. I don’t want to think about it. To be frank with you it is too soon for me to think about that, and it’s not helpful for me now. It is the opposite. It is not that I won’t think about it, I hope to be able to pace it. I think in some ways it is lucky for me, this extraordinary situation to know that you are going to die and still be well, but in some ways it is lucky because it does give you an opportunity, which you may or may not be able to make use of, to kind of plan your life properly, and I think I am doing that. I think I am making the decisions, but there are still some decisions that I’m not ready for and that sort of area is one of them. Because of that need to sort of stay focused on living for as long as I can.” M24, session 1</td>
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<tr>
<td>• May like to make a statement of wishes and preferences (15,23,37,61).</td>
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<tr>
<td>Living will document given?</td>
<td>• Gave Terrence Higgins Trust doc. (1,2,3,4,5,6,9,10,11,15,18,19,20,21,23,26,27,28,30,31,32,33,34,35,37,39,40,45,51,60).</td>
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<td></td>
<td>• Terrence Higgins Trust document completed with wife and son present during session 2 (3).</td>
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<td></td>
<td>• Didn’t give Terrence Higgins Trust doc. as patient not interested (24,29,57).</td>
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<td></td>
<td>• Terrence Higgins Trust document not mentioned during session (16,38,43,47,49,52,61).</td>
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<tr>
<td>Lasting power of attorney</td>
<td>• Didn’t know what LPA was (4,31).</td>
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<td></td>
<td>• Doesn’t want to think about LPA at the moment (20,35,40).</td>
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<td>• Doesn’t know if s/he’d want to appoint an LPA (20,39) or who she’d appoint</td>
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<tr>
<td>Resuscitation</td>
<td>Wouldn’t want to be resuscitated (18,19,23,27,29,30,32,38). Would want to be resuscitated (57).</td>
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<td>Doesn’t know whether s/he would want to be resuscitated (11,20,43).</td>
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<td>Views on resuscitation would vary depending on how ill s/he was (3,5,6,9,10,15,20,21,23,27,29,30,33,35,37,39,40,51,60,61).</td>
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<td>Would only want to be resuscitated if s/he was going to have quality of life afterwards (3,5,6,9,10,15,20,21,27,30,33,35,37,40,51). Wouldn’t want to be resuscitated if s/he died suddenly (15,21,27,33,35,39,40,51,60,61).</td>
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<td></td>
<td>Family and patient differ on what they would want at the end of life re. resuscitation (18,21,32).</td>
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<tr>
<td>Not discussed specifically</td>
<td>Not discussed extensively (16,18,39).</td>
</tr>
<tr>
<td>Changes after first ACP session</td>
<td>May talk to doctors/nurses about Terrence Higgins Trust document/future treatment options (1,37,45).</td>
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<td></td>
<td>Talked to doctors about living will after session 1 (26).</td>
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<td></td>
<td>Had looked at advance directive in between first and second sessions (3,4,6,19,21,39,51), but not completed it (1,4,6,9,19,39,51). Talked to wife about living will after first session (26). Family present at second session and had different views to patient but patient ended up making LPA during session based on their preferences (3).</td>
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<td></td>
<td>Completed LPA document (3) or discussed making future health care decisions with relatives during course of study (3,26,51).</td>
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**I. Future sessions** - At end of first session, asked whether patients wanted to meet up again and if appropriate arranged a second session or a time to call them to talk about having a second session. Same at the end of session 2.
### Arranging future sessions
- Had 1 session (2,5,11,15,18,20,21,23,24,27,28,29,30,31,32,33,34,35,37,38,40,43,45,47,49,52,57,60,61).
- Had 2 sessions (1,3,4,9,10,16,19,26,39,51). Had 3 sessions (6).
- Meeting again not discussed (21,23,32,33,38,43,45,49).
- May want to meet again for another session after seeing the doctor (1,9,19,35,39), talking to family (39), getting scan results (1,19,27,60), reading through living will (9,10,28), thinking through some of the issues (9,10,16,26,28,39,51).
- Wanted to meet again with family present (3).
- Would like to meet again if/when s/he deteriorates (24,34,35,60).
- Doesn’t want to commit to meeting up again (15,18,20).
- Tape ended abruptly so not sure if she wanted another session (47,52).

### J. Miscellaneous

#### Relatives present at session
- Wife/husband present at session 1 (49); session 2 (3,6,26,51); session 3 (6).

#### General views on ACP discussion expressed at the end of the discussion
- Made her/him feel emotional talking about these things (15,16,38,40,60,61).
- Found the conversation very useful/helpful (15,18,23,24,26,27,34,35,37,38,39,40,51).
- “I think it’s very useful possibly to have this conversation, because you do skim the surface of things quite often…. I can see the point of having a talk like this.” M23, session 1
- Allays anxiety talking about what would happen if she got ill again (23,51).
- “It is practical and nice to have this uh, foreseeing of things. If I..were to fall ill now, I’d absolutely have no fear.” M23, session 1
- Clarified things in the back of her mind (15,23,38,51).
- Thought provoking (15,16,20,23,26,28,32,33,35,38,40,51). Appreciates that s/he needs to think about these things and plan/get things in place (20,26,28,32,35,40).
- Feels like this conversation is a part of a series of steps in addressing these issues (26,28).
- “You suggested ... meeting on another couple of occasions …. I think that would be very good at that juncture, then perhaps some of what you’ve discussed will have moved on..... A series of steps.” M26, session 1
- Made her/him realise s/he wants to talk to family (1,3,15,18,19,26,27,39,51)/or health professionals (37,38,39,45).
- ACP discussion provided him/her with new information (33,34,35,37,39,40,43,45,51) – about PPC (33,37,40,45), benefits (35), living will (19,37,39), hospice day care services (45), symptom control (51).
- “There’s a bit of me that thinks ‘I don’t want to think about this, I don’t want to think about dying when I’m feeling well…. It’s not easy to talk about these things at all, but I think….all information is power.” M40, session 1
- Wants to be positive at the moment (11,33,40).
- Doesn’t need this kind of support (2,11,29).
- Doesn’t feel any better talking about things (11,29,49).
- Too early to talk about these issues (21,33,43). Not ready to fully face end of life issues yet (16,21,28,33,34,43). Will think about these issues more in the right time (16,21,26,33,34,40,43).
- “It’s made me think about things….I’ll keep it in the back of my mind and then if things get worse, I’ll, I’ll know what to do…. But I really don’t want to think about it. Most of the time I want to try and think positive.” M33, session 1
- Talking about these issues too early on may negatively affect someone’s health/prognosis (33).
- “If you make people start thinking about these things, I’m not sure whether it helps…..Obviously one has to discuss it at some stage, but discussing it early, I’m not sure is a good thing …. If.. one starts discussing everything that could possibly go wrong and how you deal with it, I think it might have a negative impact on their prognosis.” M33, session 1

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<tr>
<th>Differences between first and future sessions</th>
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<tbody>
<tr>
<td>Had 2 sessions (1,3,4,6,9,10,16,19,26,39,51). Had 3 sessions (6).</td>
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<tr>
<td>Talked to his/her partner about the future after session 1 (1,3,19,26,39,51) – living will (3,26,51); PPC (26); wishes re. blood transfusions/resuscitation (19), prognosis and the need to plan (39). Family member/s present in second session (3). They communicated about things during the session that they hadn’t communicated about before (3,51) and completed living will (3).</td>
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<tr>
<td>Talked to a friend about living will after session 1 (19).</td>
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<tr>
<td>After session 1, took steps to get in touch with hospice/talk to doctor about future (6,9,16,26,39), talk to social worker/Macmillan benefits line about benefits/counselling (1,26), talk to Macmillan nurse/CNS (6,39), get additional help for family member (26,39).</td>
</tr>
<tr>
<td>Had plans after session 1, but didn’t instigate them (1,4,6,10,51). Didn’t ask the questions s/he planned to ask doctors about the future because s/he got good news so didn’t want to bring it up (1,6,51), forgot (10). Was given Macmillan benefits line in session 1, but hadn’t called them before session 2 (4,10). In session 1 and 2, said how she wanted to involve family in difficulties with daughter but didn’t make progress with this through study (6).</td>
</tr>
<tr>
<td>Had looked through living will after session 1 (1,4,9,10,26), expressed interest in completing living will (1,4,6,9,10,26) but not completed before last session (1,4,6,9,10,26).</td>
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Appendix H: Responses to qualitative questionnaires at follow up interview

1. Clinical condition and receipt of care

1.1. Have there been any changes in your health since we last met?
No changes – 34 (52%); Improved – 17 (25%); Worsened or progressed – 13 (20%); Other – 2 (3%)

1.2. How are you feeling physically?
Some symptoms – 38 (57%) [Tiredness-25 (38%); immobility/swelling-6 (9%); pain–5 (8%); breathlessness–4 (6%); numbness-3 (5%); dizziness–1 (2%)]; Ok or good – 26 (39%); No changes – 1 (2%)

1.3. What medical care/treatment have you received since we last met?
Chemotherapy – 15 (23%); Other – 6 (9%); Radiotherapy – 2 (3%)

1.4. Have you started any new medical care or treatment since we last met?
Chemotherapy – 3 (5%); Analgesia – 3 (5%); Blood transfusion and iron – 1 (2%); Lymphatic drainage - 1 (2%); Surgery for other health problem – 1 (2%)

1.5. Have you been referred to any different health professionals since we last met?
Hospital doctor – 8 (12%); Hospice – 6 (9%); Specialist lymphoedema nurse – 1 (2%); Alternative therapy – 1 (2%)

2. Views on advance care planning

2.1 Concerns and feelings about ACP
26 patients (39%) said that they had no concerns about ACP. 56 patients (85%) said that ACP is a good idea/a positive thing.

“Very important because it allows people to understand what’s happening, their options” P37

2.2 Depends on individual and their circumstances
22 patients (33%) said the ACP discussion may not be appropriate for everyone as patients vary in how much they want to know.
“Might lead some people to panic and some people don’t like to be realistic. I like to know but other people might not.” P47

“Could be difficult as they may be in denial. It depends on their circumstances.” P32

“Overall the benefits are positive but perhaps other people might wish to make the best of time left without being given additional information they don’t want.” P37

2.3 Timing of ACP discussion important
12 (18%) patients said that the timing of the ACP discussion is important and there might be a more appropriate time to have this kind of discussion.

“At present my cancer is holding so don’t want to think about the future and plan for it. It would be helpful to see someone about planning, but only if my condition becomes worse.” P75

“Reason I haven’t done anything is I feel ok…. now is the wrong time.” P16

“Haven’t filled in advance directive. Know it’s there but not discussed it in great detail. Got what I need for when the time’s right.” P60

2.4 Emotional subject and may be difficult for some people
10 patients (15%) said that the ACP discussion may be upsetting or distressing for some people.

“Many patients don’t want to focus on the end…. Hard for people to cope with.” P76

“Was really upset after the interview. Thought I had worked it through but…it brought out a lot. “Found it difficult but helpful.” P76

“Worth doing as got a lot out of it.” P51

“It might destroy hope and panic them.” P18

2.5 Important to be given information
6 patients (9%) recognized the need for information.

“Think there should be a named person who tells you things, medical issues…. I got the answers if I asked but I did not know what to ask. There is no organised information.” P1

2.6 Skills of person conducting the ACP discussion
4 patients (6%) said that the helpfulness of the ACP discussion would depend on the skills/sensitivity of the person conducting the discussion.

“Think it could be distressing but it depends on how it’s done.” P24
2.7 *Doctors don’t have time to discuss ACP*
3 patients (5%) said they didn’t feel their doctors have time to discuss ACP.

“Concerned about if the team will have time to sit down and discuss my wishes.” P67

“Haven’t filled in advance directive, would like to do it but need a doctor to help me. There is no time in the clinic and my GP is not a specialist do I don’t know where to go.” P39

2.8 *Broaching the subject*
3 patients (5%) said that it may be difficult for health professionals to know how/when to broach the subject of ACP.

“Don’t know how you would introduce it.” P76

2.9 *Have your views changed at all since we last met? How have they changed?*
45 patients (68%) said that their views of ACP hadn’t changed since the baseline interview.
5 patients (8%) said that their views of ACP had changed since the baseline interview.

2.10 *Do you think it would be helpful for patients to discuss their future care with a health professional trained for that purpose?*
41 patients (62%) said it would be helpful/beneficial to discuss their future care with a health professional trained for that purpose.

“Yes it’s helpful – people don’t plan and don’t know what’s on offer.” P5

“Yes, I found there were many areas I had not considered. It was good to talk to [ACP mediator]. She was very knowledgeable and inspired me to think more broadly and deeply about the whole issue and in doing so, I realised how beneficial a contact she was.” P67

9 patients (14%) said the helpfulness of the discussion would depend on the individual.

“I am sure it would be for some people but not others.” P34

“Other people’s way of dealing with it may be ‘don’t want to know’, ‘want doctor to decide’, as it might destroy hope and panic them.” P18

“Depends on individual. Benefit for some people.” P45
5 patients (8%) said the helpfulness of the discussion would depend on the stage of disease or timing.

"Depends on how advanced they are." P70

3. Views on advance directives

3.1 Advance directives are a good idea/helpful
45 patients (68%) said advance directives are a good idea/helpful.

“A good idea if you can write down what you want so that it helps if you can’t make a decision at the time. Can take the burden off people in the future.” P21

“I think it can focus your mind which is the useful thing about it.” P23

“Helpful as empowers you.” P42

3.2 Unsure whether advance directives are helpful
8 patients (12%) were unsure whether advance directives are helpful.

3.3 Not relevant to think about advance directives yet
10 patients (15%) said they weren’t at the stage of needing to complete an advance directive.

“I think advance directives are good and will pursue this when my condition gets worse.” P75

“I would like to leave it for the time being.” P6

3.4 Speaking to people about advance directives
4 patients (6%) had talked to family/friends or doctor about advance directives after the ACP discussion.

“Did lead me to talk to people about decision making.” P51

3.5 Trust medical profession
3 patients (5%) said that they trusted the medical profession to make decisions on their behalf.

“Let things go as they are and let the doctors make the decision.” P22
3.6 Have your views changed at all since we last met? How have they changed?
39 patients (59%) said their views hadn’t changed since the baseline discussion. 3 patients (5%) said they didn’t know much about advance directives before, but are now better informed.

3.7 Do you foresee any particular problems with advance directives?
19 patients (29%) said they didn’t foresee any problems with advance directives. 27 patients (41%) identified potential problems with advance directives.
- 12 patients (18%) were concerned about a person changing their mind after documenting a view.
- “If somebody forms a view and then changes their mind then this could be a problem.” P2
- 5 patients (8%) said it could be difficult if a relative and patient want different things.
- “Might be hard if your family was against it.” P76
- 3 patients (5%) said there is a possibility of being misunderstood.
- 2 patients (3%) said that it is hard not knowing what the options for treatment are.
- “Main issue is knowing the options – need to be informed by doctor of options.” P42

4. Relationships with close persons and professionals

Some of the responses given in this section were difficult to interpret due to the wording of the questions. For this reason, it was not possible to summarize the responses.

4.1 Satisfaction with relationships - health professionals
43 patients (65%) said that they are satisfied with their relationships with their health professionals.

“Very satisfied with all these relationships.” P23

7 patients (11%) said that they are relatively satisfied with their relationships with their health professionals.

“Get the answers – but unsure whether you should be asking something else. Is there more information that I should know but I don’t know it because I am not asking?” P1

“As time goes by it becomes easier and feel more confident and comfortable. Initial didn’t ask or want to know – asking more.” P69

10 patients (15%) said that they are not satisfied with their relationships with their health professionals. Common reasons for this included:
- Information not readily given (4 patients – 6%)
- “The information was not really available and I had to find it out myself.” P6
- The communication was poor with the doctor (6 patients – 9%)
- Patients wanted more time with the doctor (3 patients – 5%)
- “I would like more time with the doctor….Small things would like to ask but I am conscious of the pressure on the doctors.” P18

4.2 Satisfaction with relationships — family and friends
34 patients (52%) said that they are satisfied with their relationships with their family and friends.
4 patients (6%) said that they are relatively satisfied with their relationships with their family and friends.

“Satisfied with all relationships although with friends at first they were sympathetic but now as I am not outwardly ill it’s slipped to the back of their minds.” P47

4 patients (6%) said that they are not satisfied with their relationships with their family and friends.