

## Online material

	Page
Title	2
<b>Supplement 1: COREQ checklist</b>	3
Table e1: COREQ checklist	3-7
<b>Supplement 2: Items included in the OPTION tool</b>	8
Table e2: Items included in the OPTION tool	8
<b>Supplement 3: Interview guide - Study phase 3 and 4</b>	9-10
<b>Supplement 4: Focus group guide - Study phase 5</b>	11
Table e3: Focus group guide - Study phase 5	11-12
<b>Supplement 5: Coding tree – Phase 5 (Focus Group 3)</b>	13
Table e4: Coding tree for “Palliative setting”	14
Table e5: Coding tree for “Patient assessment”	15
Table e6: Coding tree for “Presenting Options”	15
Table e7: Coding tree for “Outcomes”	15
Table e8: Coding tree for “Patient Focus”	16
Table e9: Coding tree for “Preparedness”	16
Table e10: Coding tree for “Intervention & Continuity”	16
<b>Supplement 6: Participants recruited in the study</b>	17
Table e11: Participants recruited in the study	17
<b>Supplement 7: Selected quotations</b>	17
Table e12: Selected quotations	18-26

## Title

Avoidable harm: Making decisions about chemotherapy with advanced lung cancer patients

## Authors' names

Annmarie Nelson<sup>1</sup>, Mirella Longo<sup>1</sup>, Anthony Byrne<sup>1</sup>, Stephanie Sivell<sup>1</sup>, Simon Noble<sup>1</sup>, Jason Lester<sup>2</sup>, Lesley Radley<sup>3</sup>, David Jones<sup>3</sup>, Catherine Sampson<sup>1\*</sup> and Despina Anagnostou<sup>1\*</sup>

\*Joint last authors

## Corresponding author

Full Name: Annmarie Nelson  
Department: Marie Curie Palliative Care Research Centre  
Institution: Division of Population Medicine  
School of Medicine  
Cardiff University  
UK  
Telephone Number: +44 29206 87473  
Email: [NelsonA9@cardiff.ac.uk](mailto:NelsonA9@cardiff.ac.uk)

## Supplement 1: COREQ checklist

### Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE**

**Table e1: COREQ checklist**

No. Item	Guide questions/description	Reported	Page#
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal Characteristics</i>			
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	Observations of MDT meetings (Phase 1), consultations (Phase 2) and follow up interviews (Phases 3 and 4) were carried out by Cathy Sampson and Despina Anagnostou. Facilitators to the three focus groups discussions (Phase 5) were: Stephanie Sivell, Emily Harrop, Cathy Sampson, Mirella Longo, Fiona Morgan, Despina Anagnostou. These were all staff of the Marie Curie Palliative Care Research Team at the time the study was carried out	#8-9
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Masters and PhD.	
3. Occupation	What was their occupation at the time of the study?	Research Associate and Research Fellow	
4. Gender	Was the researcher male or female?	The researchers who collected the data were all females, the study team included male researchers.	
5. Experience and training	What experience or training did the researcher have?	All researchers have hold extensive expertise in doing interviews and facilitating focus groups. They all	#9

		hold an updated GCP certificate and NVIVO training	
<i>Relationship with participants</i>			
6. Relationship established	Was a relationship established prior to study commencement?	No	#9
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	The researchers used their research experience and training to introduce the research study and mitigate the asymmetry of information between the two parties	#8
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	See reflexivity section	#9
<b>Domain 2: study design</b>			
<i>Theoretical framework</i>			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The conceptual framework used in the study is described in Fig.1	Fig. 1
<i>Participant selection</i>			
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling	#7
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	MDT members were approached and consented by the researchers (DA, CS). Patients and family/friend were approached by the clinicians recruited in the study and consented by the Marie Curie team researchers (DA, CS, ML)	#8-9

		Face-to-face interviews and focus groups were used in study Phase 3,4, and 5	
12. Sample size	How many participants were in the study?	A total of 97 participants, Table 1	Table 1
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Not recorded	#9
<i>Setting</i>			
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data was collected at the participants clinics (Study phase 1, 2, 4). Patients follow up interviews took place either at the patients' home or at the clinic (Phase 4). A hired venue was used for the consensus day where the three focus groups were run (Phase 5)	#8-9
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Yes – companions who were invited to participate and consented to the use of their data.	
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	See Table 1	Table 1
<i>Data collection</i>			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Content and face validity of the interview guide were validated from the public contributors to the study. The first interview was checked by the senior qualitative expert from the team (AN).	S2, S3
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, the interviews followed the observation of the consultation between the patient and the clinicians when planning treatment pathway	#8
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes	#8
20. Field notes	Were field notes made during and/or after the	Field notes were made during the meeting during each data collection	Ref 23

	interview or focus group?	point. Details reported in the Protocol paper (Ref 23)	
21. Duration	What was the duration of the interviews or focus group?	These are reported in Supplement 6; Table e11	S6; Table e11
22. Data saturation	Was data saturation discussed?	Data saturation was determined by the researchers' knowledge and experience	#9
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No, due to the swift trajectory of disease.	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
24. Number of data coders	How many data coders coded the data?	Three coders.	
25. Description of the coding tree	Did authors provide a description of the coding tree?	Given the lack of quotations around phase 5 we report the coding tree from one of the focus groups in Supplement 4	
26. Derivation of themes	Were themes identified in advance or derived from the data?	Both, preconceived themes related to the OPTION tool dimensions. See protocol paper for details (Ref 24). New themes emerged as the analysis progressed	#8
27. Software	What software, if applicable, was used to manage the data?	NVivo V12	#9
28. Participant checking	Did participants provide feedback on the findings?	Due to the rapid deterioration of the patients the public contributors commented on the findings	#10
<i>Reporting</i>			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, please ref to the results section	#9 to 15
30. Data and findings consistent	Was there consistency between the data presented and the	Yes, please refer to the results and discussion sections	#9 to 18

---

	findings?		
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, please ref to the results section	#9 to 15
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Because of the multi-stage and multi-method design the results section focused on the major themes. Minor themes will be presented in future publications.	

---

**Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: *Checklist*. You will NOT be able to proceed with submission unless the checklist has been uploaded. Please DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

## Supplement 2: Items included in the OPTION tool

**Table e2: Items included in the OPTION tool**

1	The clinician draws attention to an identified problem as one that requires a decision-making process	<i>Identifying the problem</i>
2	The clinician states that there is more than one way to deal with the identified problem ('equipoise')	<i>Explaining Equipoise</i>
3	The clinician assesses patient's preferred approach to receiving information to assist decision making (e.g., discussion in consultations, read printed material, assess graphical data, use videotapes or other media)	<i>Assessing preferred approach</i>
4	The clinician lists 'options' which can include the choice of 'no action'	<i>Listing options</i>
5	The clinician explains the pros and cons of options to the patient (taking 'no action' is an option)	<i>Explaining pros and cons</i>
6	The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed	<i>Exploring expectations</i>
7	The clinician explores the patient's concerns (fears) about how the problem(s) are to be managed	<i>Explaining concerns</i>
8	The clinician checks the patient has understood the information	<i>Checking understanding</i>
9	The clinician offers the patient explicit opportunities to ask questions during the decision-making process	<i>Offering opportunities for questions</i>
10	The clinician elicits the patient's preferred level of involvement in decision making	<i>Eliciting preferred involvement</i>
11	The clinician indicates the need for a decision-making (or deferring) stage (how the decision is made is not evaluated – could be paternalistic. How the decision is made between participants and who takes 'control' is not evaluated)	<i>Indicating need for decision</i>
12	The clinician indicates the need to review the decision (or deferment)	<i>Indicating need to review/defer</i>



## Supplement 3: Interview guide - Study phase 3 and 4

### Interview Schedule: Patients (Study phase 3)

1. Can you remember what you and your doctor discussed in your last consultation?
  - a) Did your doctor discuss what options for treatment may be available to you?
  - b) Which options did the doctor discuss with you?
    - *Prompt for diagnosis and potential options for treatment (including palliative care)*
2. Can you remember what the doctor told you about the treatment options available to you?
  - *Prompt for information about the risks & benefits/pros & cons of the options discussed*
  - *Prompt for any explanation about uncertainties/why these options available/consideration of palliative care*
  - *Explore understanding of the information about available treatment options and any expectations they may have about the outcome*
3. Did you feel you were given the opportunity to ask questions if there was anything you were unsure about?
4. Was a final decision on which treatment to have decided on in the consultation?
  - *Ask this question if appropriate – ie if participant has said more than one treatment option was discussed with them*
  - *Where appropriate, prompt for involvement in decision making (including whether wanting to be involved in decision making) and any explicit reference made and/or understanding that there is a decision to be made*

### Interview Schedule: Clinicians (Study phase 4)

5. How are treatment options decided on for NSCLC patients?
6. How do you present the available treatment options to your patients?
  - *Prompt for whether they present information about the risks & benefits/pros & cons of the options discussed*
  - *Prompt for any explanation given to patients about uncertainties/why these options available/consideration of palliative care?*
  - *Explore understanding of the information about available treatment options and any expectations they may have about the outcome*

7. How do you involve your patients in making decisions about their treatment?
  - *Prompt for whether they check patients' preferences for taking part in treatment decisions and whether they actively try to involve patients in treatment decisions*
  - *Prompt for whether they give time for patients to ask questions*
  - *Prompt for whether they check patients' understanding of the information they have been given*
  
8. When are 'final' decisions about the best course of action to take made? During the consultation?
  - *Check whether decisions are deferred to another time to allow patients to consider the information.*

## Supplement 4: Focus group guide - Study phase 5

**Table e3: Focus group guide - Study phase 5**

Order	Main domains	Prompt questions
	<b>Non-Small Cell Lung Cancer specific</b>	
<b>1</b>	<b>Settings*</b>	
	What happens in each setting?	What is achieved here?
	What decisions are available at the specific stage/ setting?	Which treatments are available here? Are all available options presented? (e.g. supportive care)
		Are all options available?
<b>2</b>	<b>Patient Assessment</b>	
	Performance status	Is a tool used to assess patients here (which, e.g. ECOG)? Is it adequate at this setting? If not using tool, how are patients assessed?
	Function	Do we need a shared definition of patient status (e.g. palliative care might prefer to use a functional tool e.g. <i>short physical performance battery</i> )?
	Patient/carer priorities	Are there other elements that should be assessed alongside the physical performance? e.g. Patient function in context of their daily life,  How are patients' preferences, Patients' beliefs, patient priorities, and patient expectations assessed?  Does the carer have a part to play in assessing/reporting status?
<b>3</b>	<b>Presenting options</b>	
		How are available options presented? e.g. is there a choice?  Is there equipoise? – i.e. full account of risk/benefits, consider do nothing or move to supportive care/symptom control, consider quality of life vs treatment toxicities.  How can we guide comparison of treatment options?  Do you feel that there are other options/unavailable options?  If there was a clear pathway, what other treatment options would you offer to the patients?

4	<b>Priorities</b>	What is important for the patient? What is important for the carer?
5	<b>Preparedness</b>	How does the patient communicate his/her preferences? Does the carer have an opportunity to contribute? Are patient resources available ahead of a consultation? If not, would this be useful?
6	<b>Outcomes</b>	Do patients come with prior knowledge? (internet, family, other healthcare contacts)  How should patients' preferences be conveyed to the clinician? Before or during the consultation? What outcome are we aiming for at the specific stage/setting? Outcomes relevant to the patients Outcomes relevant to the carer Outcome relevant to clinicians
7	<b>Intervention and Continuity</b>	We want to guide the patients, the carer and the clinician along the clinical pathway. How will we ensure continuous and fluid information and resources? Who should hold the intervention? should it be patient, clinician, nurse lead?
	How to best convey information?	Verbal Verbal and leaflet Electronic Video card Other

\* Each of focus group focused on a particular stage of the patients' pathway: Group A) primary care and rapid clinic, Group B) MDT meetings, Group C) Patients' consultations with the chest physician and the oncologist.

## **Supplement 5: Coding tree – Phase 5 (Focus Group 3)**

Table e4: Coding tree for “Palliative setting”

Table e5: Coding tree for “Patient assessment”

Table e6: Coding tree for “Presenting Options”

Table e7: Coding tree for “Outcomes”

Table e8: Coding tree for “Patient Focus”

Table e9: Coding tree for “Preparedness”

Table e10: Coding tree for “Intervention & Continuity”

**Table e4: Coding tree for “Palliative setting”**

<input type="radio"/>	Palliative setting
<input type="radio"/>	A&E
<input type="radio"/>	Abandonment as barrier to palliative care
<input type="radio"/>	Continuity of care between oncologist and palliative
<input type="radio"/>	Cultural perception of death
<input type="radio"/>	Palliative terminology challenge
<input type="radio"/>	Professional challenges
<input type="radio"/>	Chest physician
<input type="radio"/>	<input type="radio"/> CNS at chest physician consultation
<input type="radio"/>	<input type="radio"/> Not an expert
<input type="radio"/>	<input type="radio"/> Takes ownership
<input type="radio"/>	<input type="radio"/> Treatment is the only choice
<input type="radio"/>	Keyworker
<input type="radio"/>	<input type="radio"/> CNS as keyworker
<input type="radio"/>	<input type="radio"/> Need for early keyworker involvement
<input type="radio"/>	<input type="radio"/> Patient as keyworker
<input type="radio"/>	<input type="radio"/> Late introduction of the patient
<input type="radio"/>	MDT
<input type="radio"/>	<input type="radio"/> Function and purpose
<input type="radio"/>	<input type="radio"/> Non inclusive of CNS
<input type="radio"/>	<input type="radio"/> Performing expertise
<input type="radio"/>	Oncologist perspective
<input type="radio"/>	<input type="radio"/> Challenge to role perception
<input type="radio"/>	<input type="radio"/> Consistency of information
<input type="radio"/>	<input type="radio"/> Difficulty including palliative option
<input type="radio"/>	<input type="radio"/> Information overload
<input type="radio"/>	<input type="radio"/> Just do as told
<input type="radio"/>	<input type="radio"/> Mindset of diagnostic over palliation
<input type="radio"/>	<input type="radio"/> Not rubbishing colleagues
<input type="radio"/>	<input type="radio"/> Pathway time pressure
<input type="radio"/>	<input type="radio"/> Patient presentation
<input type="radio"/>	<input type="radio"/> Patient treatment understanding
<input type="radio"/>	<input type="radio"/> Permission not to have treatment
<input type="radio"/>	<input type="radio"/> Unpicking patient knowledge
<input type="radio"/>	Professional communication skills
<input type="radio"/>	Professional role issues
<input type="radio"/>	Symptom palliation treatment priority
<input type="radio"/>	<input type="radio"/> Symptom palliation and hope
<input type="radio"/>	Territorial pathways

**Table e5: Coding tree for “Patient assessment”**

<input type="checkbox"/>	Patient assessment	
	<input type="checkbox"/>	Performance Status
		<input type="checkbox"/> Oncologist perspective
		<input type="checkbox"/> Can be manipulated for treatment
		<input type="checkbox"/> Should know patient
	<input type="checkbox"/>	Patient performance status self-assessment
	<input type="checkbox"/>	Using existing patient self-assessment tools
	<input type="checkbox"/>	Holistic Needs Assessment

**Table e6: Coding tree for “Presenting Options”**

<input type="checkbox"/>	Presenting Options	
	<input type="checkbox"/>	Challenges
		<input type="checkbox"/> Active versus Passive perception
		<input type="checkbox"/> Are all options included
		<input type="checkbox"/> Limited by professional opinion
		<input type="checkbox"/> Not appropriate
		<input type="checkbox"/> Patient deference
		<input type="checkbox"/> Too complex
		<input type="checkbox"/> Too time consuming
	<input type="checkbox"/>	Explaining pros and cons
	<input type="checkbox"/>	Suggestions
		<input type="checkbox"/> Alternative therapies
		<input type="checkbox"/> Consultation over two visits
		<input type="checkbox"/> Information and educational
		<input type="checkbox"/> Reflection and Planning
		<input type="checkbox"/> Framing options in positive way
		<input type="checkbox"/> Is different pathway needed
		<input type="checkbox"/> Non publicly funded options
		<input type="checkbox"/> Prompt questions for patients around options
		<input type="checkbox"/> Should be presented by oncologist

**Table e7: Coding tree for “Outcomes”**

<input type="checkbox"/>	Outcomes	
	<input type="checkbox"/>	Oncologist
		<input type="checkbox"/> Driven by oncologist own role perception
	<input type="checkbox"/>	Patient priorities
		<input type="checkbox"/> Quality of life
		<input type="checkbox"/> Support
		<input type="checkbox"/> Symptom relief

**Table e8: Coding tree for “Patient Focus”**

<input type="radio"/>	Patient Focus
<input type="radio"/>	Patient expectations
<input type="radio"/>	Patient preparation
<input type="radio"/>	Cancer understanding
<input type="radio"/>	Information and question pack
<input type="radio"/>	Information groups
<input type="radio"/>	Navigating processes and personnel
<input type="radio"/>	Patient understanding of decision-making agenda
<input type="radio"/>	Permission to ask questions
<input type="radio"/>	Prognosis
<input type="radio"/>	Setting own agenda
<input type="radio"/>	Patient priorities
<input type="radio"/>	Eliciting values and priorities
<input type="radio"/>	Patient reflection
<input type="radio"/>	Opportunity to provide info on priorities
<input type="radio"/>	Opportunity to reflect on priorities
<input type="radio"/>	Treatment priorities

**Table e9: Coding tree for “Preparedness”**

<input type="radio"/>	Preparedness
<input type="radio"/>	Accountability of information
<input type="radio"/>	Challenge of communication
<input type="radio"/>	Information for the oncologist
<input type="radio"/>	Letters to patient
<input type="radio"/>	Multimedia
<input type="radio"/>	Patient perspective
<input type="radio"/>	Complex language
<input type="radio"/>	Educational groups
<input type="radio"/>	Range of needs
<input type="radio"/>	Transcript of consultation
<input type="radio"/>	Signposting
<input type="radio"/>	Sources
<input type="radio"/>	Tailored for different patient and carer needs
<input type="radio"/>	Tailored to different coping styles

**Table e10: Coding tree for “Intervention & Continuity”**

<input type="radio"/>	Intervention & Continuity
<input type="radio"/>	Drawbacks about patient held
<input type="radio"/>	Electronic record
<input type="radio"/>	Patient held paper record



## Supplement 6: Participants recruited in the study

**Table e11: Participants recruited in the study**

Study participants		Data capture events		Audio recording Minutes mean (Range)
Phases 1-4				
Health care professionals	51	Observation of MDT meetings	13	77 (25 to 160)
Patients with advanced NSCLC	15	Observation of consultations	15	31 (18 to 63)
Families	15	Patient- carer interviews	9	34 (18 to 58)
		Clinician interviews	17	34 (8 to 72)
Phase 5 (consensus)				
Consensus focus groups	18	Expert consensus groups	3	67 (63 to 74)
<b>Total</b>	<b>99</b>	<b>Total</b>	<b>57</b>	

## Supplement 7: Selected quotations

**Table e12: Selected quotations**

Reference	Context	Quotation
Quotation 1	Study phase 1 - MDT meeting  (Site 1 – MDT 1)	<b>Chest physician...</b> um next then is (PATIENT NAME) who we discussed previously at the MDT... <i>[Three weeks before]</i> she's was performance status one she's undergone bronchoscopy which shows some abnormal mucosa...biopsies did not confirm malignancy...radiologically it looked like a tumour...border line candidate for radical radiotherapy...lesion were benign so we were going to arrange a CT guided biopsy for histological confirmation and await the result of the PET scan which was in progress so um CT biopsy
Quotation 2	Study phase 3 – Follow up interviews with patients  (Site 3 – Patient 1)	<b>Interviewer:</b> Did she discuss what treatments were available to you then? <b>Patient:</b> Well chemotherapy and something then after about three months some sort of um radio radiotherapy or ... what whatever you call I don't know ... radiothe <b>Interviewer:</b> Yeah radiotherapy <b>Patient:</b> Yeah <b>Interviewer:</b> Um was it just those that she didn't cos she didn't discuss any other options with you? <b>Patient:</b> No <b>Companion:</b> No <b>Patient:</b> No ...not that not that I was aware of <b>Companion:</b> No she didn't <b>Patient:</b> Sshh a minute (WIFE NAME) <b>Companion:</b> (laughs) <b>Interviewer:</b> So it is so chemotherapy and then radiotherapy after <b>Patient:</b> Three months or so yeah <b>Interviewer:</b> Three months <b>Patient:</b> Yeah

		<p><b>Interviewer:</b> Okay ... and was that for the ... lung cancer or was that for ... the cos you said she said that's for other parts</p> <p><b>Patient:</b> Well I don't know I think it might have been for the whole five I don't know</p> <p><b>Interviewer:</b> Right okay</p> <p><b>Patient:</b> Yeah you know ... the nurse (CNS NAME) ...I did ask her in the end and she tried to read out what these five were</p> <p><b>Interviewer:</b> right</p>
Quotation 3	<p>Study phase 2 - Oncology clinic consultation</p> <p>(Site 2 – Consultation 1)</p>	<p><b>Patient:</b> What I (...) I suppose I'm concerned about is prognosis</p> <p><b>Oncologist:</b> Yeah</p> <p><b>Patient:</b> Is the amount</p> <p><b>Oncologist:</b> How long question</p> <p><b>Patient:</b> Yes</p> <p><b>Companion:</b> ...We were going to rephrase that</p> <p><b>Patient:</b> ...We have a holiday booked in a year next December</p> <p><b>Companion:</b> Yes so what rather than say specifically what are the chances of going on a holiday in a year's time year December?</p> <p><b>Oncologist:</b> If I'm honest the majority of patients with a cancer as advanced as yours even with treatment the majority would not be alive in a year</p> <p><b>Patient:</b> Really?</p> <p><b>Oncologist:</b> Mm</p> <p><b>Companion:</b> Gosh</p> <p><b>Oncologist:</b> That is an average so everyone's different depending</p> <p><b>Companion:</b> Mm</p> <p><b>Oncologist:</b> On how they respond to the chemo and their general wellbeing</p> <p><b>Patient:</b> Right that's a bit of a shock</p>

Quotation 4	Study phase 3 – Follow up interviews with patients  (Site 2 – Patient 1)	<b>Patient:</b> Um so when we saw her [ <i>The chest physician</i> ]...maybe we were asked a couple of questions about...the treatment chemotherapy...and we asked about...holidays booked...did she think...we...should cancel them...oh no she said...no carry on have something to look forward to obviously the immediate holidays we were...cancelling um and we'd already started to do that no she said people can live...can lead um perfectly normal lives...even during chemotherapy and after the chemotherapy...no have something to look forward to...I didn't say all this with (ONCOLOGIST NAME) of course we had...seen her [ <i>The chest physician</i> ] the...week before yes...And so we were quite buoyed with her um approach
Quotation 5	Study phase 2 - Oncology clinic consultation  (Site 1 - Consultation 3)	<b>Oncologist:</b> Well you've got to choose what's right for you and that's why there's a range of different approaches but the best person to decide which is going to work for you is probably yourself not us <b>Patient:</b> As long as I can get my breathing under control I'm happy <b>Companion:</b> Yeah <b>Oncologist:</b> Okay <b>Patient:</b> I go out in my garden <b>Oncologist:</b> Okay <b>Patient:</b> Cut my grass and <b>Oncologist:</b> Okay <b>Patient:</b> That's all I want to do <b>Companion:</b> See 'cos I got Alzheimer's as well <b>Oncologist:</b> Oh really... I didn't know that <b>Patient:</b> I focus on trying to control my breathing...that's all I want to do...she got Alzheimer's I got to look after her it's what I do

Quotation 6	Study phase 2 - Oncology clinic consultation  (Site 2 - Consultation 2)	<p><b>Companion:</b> It sort of seems to me that what you say this course of chemo works but not to any great extent</p> <p><b>Oncologist:</b> Mmm</p> <p><b>Companion:</b> So maybe a trial would be you never know it might be better it could hardly be worse it's what I'm saying so</p> <p><b>Oncologist:</b> Yeah</p> <p><b>Companion:</b> Um but we don't have the option to join that anyway</p> <p><b>Oncologist:</b> No (...) what if we gave you an information leaflet about the chemotherapy and just gave you some time to think about it?</p> <p><b>Patient:</b> I think we will go for the chemotherapy</p> <p><b>Companion:</b> Yeah fine yeah that's fine</p> <p><b>Patient:</b> Is that all right?</p> <p><b>Oncologist:</b> Um okay</p> <p><b>Patient:</b> Because without the chemotherapy there's no chance at all</p>
Quotation 7	Study phase 2 - Oncology clinic consultation  (Site 3 - Consultation 4)	<p><b>Companion:</b> Yeah it's what she's saying dad is that if you had the chemo now and you're not quite up to it strong enough for it</p> <p><b>Patient:</b> I'm not strong enough am I?</p> <p><b>Companion:</b> You could have side-effects and you could end up in bed and no appetite and sick and things</p> <p><b>Patient:</b> Yeah</p> <p><b>Clinical nurse specialist:</b> And have no quality of life then</p> <p><b>Companion:</b> And then you'd feel worse</p> <p><b>Patient:</b> Yeah</p> <p><b>Companion:</b> And it's not doing any good for you or you stay as you are at the moment</p> <p><b>Patient:</b> Yeah</p>
Quotation 8	Study phase 2 - Oncology clinic consultation	<p><b>Companion:</b> ...What's the palliative that word you said then palliative?</p> <p><b>Oncologist:</b> ...What it really means is...to cloak...to kind of just cover up and suppress and control essentially</p> <p><b>Companion:</b> Yeah</p> <p><b>Oncologist:</b> So it means it's not a cure</p> <p><b>Companion:</b> Right no</p>

	(Site 1 - Consultation 1)	<p><b>Oncologist:</b> It's...looking at just trying to control things to slow things down</p> <p><b>Companion:</b> So I was going to say cos</p> <p><b>Patient:</b> That's what a palliative nurse does</p> <p><b>Companion:</b> I got it confused cos I thought it was treatment and then palliative being last but it's not</p> <p><b>Oncologist:</b> No ... that's right no (...) no sometimes people think palliative care means end of life</p> <p><b>Companion:</b> Yeah that that's right</p> <p><b>Oncologist:</b> But...all it means is to just help people</p> <p><b>Companion:</b> To control it yeah keep it yeah that's</p> <p><b>Oncologist:</b> Control symptoms yeah</p> <p><b>Companion:</b> Okay</p> <p><b>Oncologist:</b> Yeah</p>
Quotation 9	<p>Study phase 1 - MDT meeting</p> <p>(Site 3 – MDT 2)</p>	<p><b>Chest physician:</b> Is he still an inpatient?</p> <p><b>Clinical nurse specialist:</b> No he's at home now</p> <p><b>Chest physician:</b> He's gone home and his performance status is still one?</p> <p><b>Clinical nurse specialist:</b> It's no it's changing I've asked the GP to go out and I've spoke to the family this morning he's deteriorating quite rapidly</p> <p><b>Chest physician:</b> Okay (...) okay and why is that is that because of headaches or just general deterioration or</p> <p><b>Clinical nurse specialist:</b> No general deterioration</p> <p><b>Chest physician:</b> Okay</p> <p><b>Clinical nurse specialist:</b> He is spending most of his time in bed his family have come up to stay with him and his GP has started him on some MST and I've asked the GP to review again</p> <p><b>Chest physician:</b> So his performance status is that at least two if not anymore three</p> <p><b>Oncologist:</b> And then the performance status is two or three then</p> <p><b>Chest physician:</b> Yeah two or three yeah</p> <p><b>Clinical nurse specialist:</b> Yeah two to three at the moment</p>

Quotation 10	Study phase 2 - Oncology clinic consultation  (Site 1 – Consultation 1)	<p><b>Oncologist:</b> Good okay so you obviously been through a difficult time ... what do you understand the problem is?</p> <p><b>Patient:</b> I understand that the only thing I don't want to know doctor I'll be honest with you I don't want to know my time limit</p> <p><b>Oncologist:</b> Okay that's fine</p> <p><b>Patient:</b> Because we've all got a lifespan haven't we and I really don't want to I think that I couldn't cope with that but I do realise and appreciate the fact that I have got something that's not curable but treatable that's what I've been told</p> <p><b>Oncologist:</b> Okay that's that's so</p> <p><b>Patient:</b> And that they can keep it under control</p> <p><b>Oncologist:</b> Okay well that's what you see me about</p> <p><b>Patient:</b> Right right</p> <p><b>Oncologist:</b> Okay</p> <p><b>Patient:</b> Okay</p> <p><b>Oncologist:</b> Okay alright so I will give you the information you want</p> <p><b>Patient:</b> Right</p> <p><b>Oncologist:</b> You just stop me at any point if</p> <p><b>Patient:</b> Yeah</p> <p><b>Oncologist:</b> You don't want to know anymore</p> <p><b>Patient:</b> Yeah</p> <p><b>Oncologist:</b> Okay</p>
Quotation 11	Study phase 2 - Oncology clinic consultation  (Site 2 – consultation 3)	<p><b>Oncologist:</b> But unfortunately some people feel so poorly that you know that we don't think that we're doing the right thing so we'd have to see how you went really</p> <p><b>Patient:</b> Okay yeah yeah</p> <p><b>Oncologist:</b> But we can certainly offer you some chemotherapy</p> <p><b>Patient:</b> But...sort of things like that I've always been fairly resilient anyway</p> <p><b>Oncologist:</b> Yeah some people decide not to have treatment and then we offer what we call best supportive care so we just treat some of the symptoms of the cancer as they arise so for example just improve your pain killers if you had pain um we'll try and help you with your breathing should you become breathless</p>

		<p><b>Patient:</b> Mm mm</p> <p><b>Oncologist:</b> But that would not be sort of active treatment and at the moment you're fit enough for us to offer you chemotherapy should that</p> <p><b>Patient:</b> Yeah yeah</p> <p><b>Oncologist:</b> Be something that you wanted to consider</p> <p><b>Patient:</b> I think so yeah</p> <p><b>Oncologist:</b> Yeah</p> <p><b>Companion:</b> I do as well</p>
Quotation 12	Study phase 2 - Oncology clinic consultation  (Site 3 - Consultation 2)	<p><b>Oncologist:</b> Are you also concerned about timing? about life expectancy? Any questions you'd like to ask today</p> <p><b>Patient:</b> Life expectancy that's a good one</p> <p><b>Oncologist:</b> Would you like to know I mean</p> <p><b>Patient:</b> Yeah sure go on</p> <p><b>Oncologist:</b> So...the extension of the disease conditions are...a time limit...of around eight months</p> <p><b>Patient:</b> There we are then</p> <p><b>Oncologist:</b> And these can be extended and improved with the chemotherapy as long as there's a response by three to four months</p> <p><b>Patient:</b> There we are</p> <p><b>Oncologist:</b> Some patients made better other made worse they are also subsequent lines of treatment that could enlarge these further as long as your general condition remains resettable</p>



Quotation 13	Study phase 4 – Follow up interview with the clinician  (Site 2 - Clinician 3)	<p><b>Oncologist:</b> Yeah I mean I try not to use words like palliative to patients cos they may not understand it</p> <p><b>Interviewer:</b> Yes</p> <p><b>Oncologist:</b> Um but so I'm I suppose from the point of view an oncologist I'd like to offer them to see if there's treatments they can benefit from...then explain those treatments like radiotherapy or chemotherapy and also obviously manage some of their symptoms with other things but if they have a more specialised if they have a more difficult symptom</p> <p><b>Interviewer:</b> Yes they</p> <p><b>Oncologist:</b> Um that is more tricky to manage then then um the specialist palliative care consultant will have more to offer them</p> <p><b>Interviewer:</b> Yes</p> <p><b>Oncologist:</b> So you're usually seeing both is useful in that</p>
Quotation 14	Study phase 2 - Oncology clinic consultation  (Site 2 - consultation 5)	<p><b>Oncologist:</b> So really any treatments that we discuss today first there's two aims one of them is to improve your symptoms so for example if we can do something to help with the pain...and then there are some treatments like chemotherapy that can improve your symptoms</p> <p><b>Patient:</b> Yeah</p> <p><b>Oncologist:</b> And also potential how long you live with the cancer</p> <p><b>Patient:</b> Yeah but I</p> <p><b>Oncologist:</b> Um</p> <p><b>Patient:</b> Want quality of life</p> <p><b>Oncologist:</b> Okay</p> <p><b>Patient:</b> Doctor you know</p> <p><b>Oncologist:</b> Yeah</p> <p><b>Patient:</b> Quantity doesn't mean a lot if there's no quality</p> <p><b>Oncologist:</b> Well I absolutely agree with you on that and I think that's the crux of this really</p> <p><b>Patient:</b> Right</p> <p><b>Oncologist:</b> Um and everyone's very different in their view on that you know</p> <p><b>Patient:</b> I don't believe in life at any price I don't</p>

**Text key:**

(...) = Pause

... = Text omitted to shorten extract (e.g. er, uhm)

[*Italics*] = Inserted text for context

(CAPITALS) = Anonymised text