

**Title:** A question prompt list for patients with advanced cancer in the final year of life: Development and cross-cultural evaluation

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## **Abstract**

**Background:** Clinicians and patients find prognosis and end-of-life care discussions challenging. Misunderstanding one's prognosis can contribute to poor decision-making and end-of-life quality-of-life. A Question Prompt List (QPL – booklet of questions patients can ask clinicians) targeting these issues may help overcome communication barriers. None exists for end-of-life discussions outside the palliative care setting.

**Aim:** To develop/pilot a QPL facilitating discussion/planning of end-of-life care for oncology patients with advanced cancer from Australia and the USA and explore: acceptability, perceived benefits/challenges of using the QPL, suggestions for improvements and the necessity of country specific adaptations.

**Design:** An expert panel developed a QPL targeting prognosis and end-of-life issues. Australian/US semi-structured interviews and 1 focus group elicited feedback about the QPL. Transcribed data were analysed using qualitative methods.

**Setting/participants:** Thirty-four patients with advanced cancer (15 Australian/19 US) and 13 health professionals treating such patients (7 Australian/6 US) from 2 Australian and 1 US cancer centre participated.

**Results:** Most endorsed the entire QPL, though a minority queried the utility/appropriateness of some questions. Analysis identified four global themes: 1) reinforcement of known benefits of QPLs, 2) appraisal of content and suggestions for further developments, 3) perceived benefits and challenges in using the QPL and 4) contrasts in Australian/US feedback. These contrasts necessitated distinct Australian/US final versions of the QPL.

**Conclusions:** Participants endorsed the QPL as acceptable and useful. Feedback resulted in two distinct versions of the QPL, accommodating differences between Australian and US approaches to end-of-life discussions, highlighting the appropriateness of tailoring communication aides to individual populations.

**Key words:** question prompt list, advanced cancer, terminal care, cross-cultural comparison, communication, qualitative research

## **Introduction**

Over a third of adult patients with cancer die prematurely of their disease, many experiencing sub-optimal end-of-life care. [1,2] Patients often do not discuss prognosis or end-of-life care with their doctor or family [3-5] though most desire such discussions [6]. This can contribute to inappropriate end-of-life care choices, increased suffering and possibly decreased survival. [7,8]

Clinicians may be unsure how much patients want to know and worry about destroying hope [9] while patients may not know what to ask or how or feel unprepared for the answers [10]. Question Prompt Lists (QPLs – booklets containing categorised lists of useful questions patients can ask their clinician) can assist in overcoming these barriers. Increased patient question asking and decreased unmet information needs have been seen in randomised controlled trials of QPLs [11,12] with patients finding them more helpful than receiving written information alone as they assist them with formulating questions. [13]

QPLs have been developed for patients seeing medical oncologists, radiation oncologists or surgeons for the first time, [14,15] and patients and carers newly referred to palliative care. [16] No QPL has been developed for patients with advanced cancer outside the palliative care setting. Such patients newly face deterioration and eventual death, experiencing challenges in eliciting and adapting to information about prognosis and end-of-life issues. As they remain well enough to participate in Advance Care Planning (ACP),

ensuring their end-of-life needs and wishes are respected, they have the potential to benefit greatly from such a QPL.

Little cross-cultural data exists regarding such communication aids [17] and health system differences and cultural factors may influence content, delivery and impact of QPLs. While both favouring disclosure and discussion of prognosis and end-of-life issues, [18] Australia and the United States of America (US) have marked differences in end-of-life healthcare models, [19,20] including the presence in Australia and absence in the US of national end-of-life care policies, differing availability of palliative care consultations and services, and dissimilar conditions of access to care and location of care facilities. [20]

The QPL piloted in this paper was developed to facilitate discussion and planning of end-of-life care and associated issues with Australian and US patients who have advanced cancer and are likely to die within 12 months. Content was guided by factors identified as important at the end-of-life by patients, family, physicians and care providers [21,22]. We sought to explore the acceptability, perceived benefits and challenges of using this QPL, elicit suggestions for improvement and determine the necessity of country specific adaptations of the QPL.

## **Methods**

### **Initial question prompt list development**

Questions were developed and refined in Australia by an expert panel of seven health communication researchers and health professionals from psychology, medical oncology, palliative care, critical care nursing and family medicine disciplines. Guided by panel members' knowledge, selected relevant literature was consulted and several existing QPLs were sourced from database searches of studies published since 1950 or requested

from authors. [14-16,21-24] Where possible, items were adapted from existing QPLs if they focussed on issues relevant for the target population and purpose of the QPL including; prognosis, treatment options and decisions with non-curative intent, end-of-life issues, ACP and supportive or palliative care services for the patient, carer or family. Where existing items covering target issues were not available, new items were drafted. The panel then established item and topic orders in the QPL, drafted introductory and instructional texts to precede the first section and reviewed the content and structure of this initial QPL for clarity and acceptability. US researchers reviewed the initial QPL to ensure cultural appropriateness in their setting. Several changes were necessary, including the removal or reordering of some questions and sections and use of US rather than Australian idiomatic expressions. The resulting Australian and US initial QPLs are presented in Appendix 1.

### **Participants and procedure**

English-speaking adult patients with advanced, incurable cancer and a life expectancy (assessed by their oncologist) of less than 12 months, and oncology and palliative care doctors and nurses who treat such patients participated. Members of the research team identified and invited health professionals meeting selection criteria from one US and two Australian treatment centres to participate in the study. Consenting oncologists identified consecutive patients meeting selection criteria when they attended consultations and research assistants approached identified patients to obtain informed consent to participate.

Participants elected to join a focus group or complete an individual, semi-structured interview conducted by research assistants trained in qualitative methods. Interviews were offered to facilitate the participation of individuals who were unable or unwilling to join a

focus group. Participants completed a short questionnaire eliciting demographic and disease or professional details and were given the QPL and a short time to become familiar with the content before beginning the interview/focus group. In accordance with established qualitative research protocols, sampling was discontinued when information redundancy was reached, with three consecutive interviews yielding no additional information. [25] Each interview and the focus group were audio-recorded and transcribed verbatim.

Sydney South West and Northern Sydney Central Coast Area Health Services Ethics Committees in Australia and the University of Rochester Research Subjects Review Board in the US granted ethical approval.

### **Measures and interviews/focus group**

Elicited demographic details included age, gender, educational attainment, primary tumour site and treatments received for patients, and age, gender, experience, communication training and specialty for health professionals. During the interview/focus group, participants were invited to comment on the clarity, relevance and appropriateness of the QPL content, potential barriers and facilitators to its use, and suggest any additions, deletions and changes they felt were appropriate.

### **Analysis**

The research team reviewed and interpreted transcripts using thematic text analysis with an inductive, data-driven approach, [25-27] managed with Atlas.ti. [28] Consistent with this method, Australian and US researchers (AW/BM) independently developed codes representing underlying meanings in the text. Interview and focus group data did not appear to systematically differ by participation method and were analysed collectively. The

research team regularly compared and discussed code names and definitions to resolve areas of disagreement. A random sample of 12 transcripts was double coded to ensure agreement between the two coders. Through iterative reading of data grouped by codes, recurrent themes and illustrative examples were established. Comparison was made between coded Australian and US transcripts to discern points of commonality and divergence. Successive rounds of iterative discussion and resolution of code names, definitions and themes and review of the coding process by team members not directly involved in developing the coding framework ensured methodological rigour. [29]

## **Results**

### **Participant Characteristics**

Fifteen Australian and 11 US patients completed individual interviews and 8 US patients joined a focus group (see Table 1). Australian patients were predominantly male (80%), mean age 67 years. Most had primary lung cancer (60%), and 11 of the 15 had received chemotherapy, 6 radiotherapy and 7 surgery. US patients were predominantly female (68%), mean age 58 years. While individual US data were not obtained, primary diagnoses included colon, breast, lung, pancreas or prostate cancers with progression during chemotherapy.

Insert Table 1 here

Seven Australian and 6 US health professionals completed individual interviews (see Table 2). Australian health professionals were predominately male (57%), mean age 45 years. Two were medical oncologists, one a radiation oncologist, three were oncology nurses and one a palliative care nurse with 13 years experience in their field on average. Three had completed postgraduate communication skills training. US health professionals

were predominantly female (67%). All were medical oncologists with 16 years experience on average. Four had completed postgraduate communication skills training.

Insert Table 2 here

## **Themes**

There was broad commonality in patients' and health professionals' responses and the themes described below reflect both participant groups. Variations in participants' feedback did not appear to be systematically related to demographic factors. Differences between the two groups' feedback are highlighted where present. Four global themes were identified: *Reinforcement of known general benefits of QPLs, Appraisal of the QPL content and suggestions for further developments, Perceived benefits and challenges in using a QPL focussing on end-of-life issues and Contrasts between Australian and US feedback*. These themes are discussed in detail below and illustrated with participants' quotes, chosen for their ability to succinctly illustrate themes and sub-themes. Quotes represent the perspectives of multiple participants.

### Reinforcement of known general benefits of QPLs

Patient and health professional participants provided largely positive feedback about the QPL, reinforcing previously identified general benefits of QPLs. Some indicated that the QPL could ensure patients' information needs would be met if their doctor were not an optimal communicator while others noted it would help patients remember questions they wished to ask.

**Helpful if doctor is not an optimal communicator** – *“You’ve got ten thousand questions running around in your head... if you have a specialist not exactly full of people skills, then this would (help the discussion)” (Au Patient 01)*

**Help to remember questions** – *“You go in and you think ‘I’ll ask them this’ and then you forget. And then you go home and you think ‘should’ve asked that...’ So if you’ve got (this and) you ask a couple of questions each time, that’s not a bad idea” (Au Patient 03)*

Patients suggested this could help manage information overload commonly experienced in this setting, with some describing independently writing down questions for their doctor for this purpose. Patients also noted that the QPL prompted consideration of issues they were previously unaware of.

**Help to manage information overload** – *“I think this definitely a good booklet. It would be very helpful for people that don’t write down questions before they go into appointments with their oncologist” (US Patient 01)*

**Prompted consideration of new issues** – *I never have and probably never would have thought to ask a question like that. So, that’s a good one to actually ask. (US patient 09)*

#### Appraisal of the QPL content and suggestions for further developments

Patients and health professionals mostly endorsed the content of the QPL, indicating that it was comprehensive and achieved its aims. Most questions were regarded as appropriate and important, with only a small minority critiquing some items.

**Appropriate content** – *“I think they’re all good questions. I think some patients would find them quite difficult (but) it doesn’t mean they shouldn’t be asked.” (Au Health Professional 01)*

Several participants, principally in the US patient sample, displayed ambivalence towards end-of-life questions (e.g. US Initial Version – section 4 “What I can expect” and section 6

“If treatment doesn’t work” and Australian Initial Version – section 1 “My cancer and what to expect in the future” and section 6 “Preparing for the end-of-life”), mostly indicating that while they were “good,” they would perhaps be more relevant later or for other people.

**Good but more relevant for others** – *“They were excellent questions, they don’t apply to me but other people” (Au Patient 02)*

**Good but more relevant at another time** – *“There’s some questions in there you don’t really want to ask – not yet, maybe later” (Au Patient 10)*

Some questions were considered personally irrelevant due to patients’ outlook (e.g. Who can I talk to about my religious, spiritual or emotional needs?), coping style (e.g. Is it possible to give me a time frame?) or a high likelihood that information would be volunteered without a specific query (e.g. What kind of cancer do I have?).

**Personally irrelevant due to outlook** – *“Well, basically I think I’ve got a good doctor in Dr (name) and I’m happy to be guided by her” (Au Patient 06)*

**Personally irrelevant due to coping style** – *“I have never had difficulty making an important decision ever in my entire life... you simply see what the situation actually is and you fit in with it... I’m not a discussor of these matters with anyone” (Au Patient 08)*

**Personally irrelevant due to volunteered information** – *“Well, they tell me that right when I walk in. I don’t even ask those questions” (US Patient 01)*

Patients and health professionals alike indicated that an oncologist might not be the ideal person to ask certain questions, citing greater availability or expertise from other information sources (e.g. US Initial Version – section 5 “What I can do” and Australian Initial Version – section 5 “Support for me and my family” financial assistance question).

**Doctor potentially not ideal person to ask** – *“I can’t understand what this (financial support) part is... What can (the doctor) do for you? (Au Patient 10)*

Importantly, all participants advocated retaining rather than eliminating questions, even those thought to be irrelevant or difficult to approach or answer, as different patients or their own shifting priorities might render them useful.

#### Perceived benefits and challenges in using a QPL focussing on end-of-life issues

All patients and most health professionals endorsed the overall beneficence of this QPL for this point in the cancer trajectory with many describing specific benefits and challenges they envisaged in using an end-of-life focussed QPL. Several patients indicated they would have benefitted from receiving this QPL when first informed that their cancer was incurable and that this was the ideal time to provide the QPL.

**Personally beneficial and should be used near disclosure of incurability** – *“As an aid I think it’s very effective and I only wish I had that in my hot little hand when I was first told about it... I think it might have saved a lot of grief” (Au Patient 01)*

**Should be used early** – *“I wish we would have gotten something like this when we first started, just something this basic. (US Patient 03)*

Some reported that they would consider discussing issues such as ACP and palliative care having read the QPL. Additionally, one patient highlighted the potential importance of these questions to carers, describing the transference of illness burdens from patient to carer as the disease progressed.

**Would now consider discussing palliative care, ACP** – *“(Advance care planning) I haven't even considered... I will have to start looking at that... Is there a way to plan and document my wishes? Well, I can tell my executor who's a friend of 40 years; mind you she may not know that I was in hospital... I really need to talk to somebody about this. And I will.” (Au patient 06)*

**Importance to carers** – *“I think these questions definitely need to be in the pamphlet... not only for the patient but for the caregiver as well if there is one involved... most of the stress will probably be put on them and not the patient” (US Patient 05)*

Interestingly, while patients emphasised that the QPL would encourage more questions during consultations, helping them acquire more information, some health professionals were reluctant to see increased question asking, highlighting the need to moderate it during consultations due to ubiquitous time pressures.

**Health Professionals advocating need to moderate patient question asking** – *“I think that you should stress that although these are all important questions; these may be addressed over several visits, rather than just one visit” (US Health Professional 01)*

One patient noted that questions related to life expectancy may be harmful if incorrect information was given, delivered insensitively, or if the recipient were young. Other participants appeared similarly cautious about discussing life expectancy, though none explicitly identified aspects deserving caution, despite interviewers' prompts to elaborate.

**Life expectancy questions deserve caution** – *“That could really hurt some people. When I was 21, I was told I had six months to live, incurable. Not worth operating on*

*because it'd be spread throughout my body... I nearly went out and went under a train"*

*(Au Patient 06)*

Several patients also highlighted the potential futility of asking questions. Some noted that oncologists might not respond to queries or do so in an unhelpful or undesirable way.

Others cited spiritual or epistemological perspectives when explaining this sense of futility.

**Patients' sense of futility in asking questions due to response** – *"All doctors and specialists are the same, they don't like to say, "you can expect this," because people are different in their responses to different diseases, and so I don't get quite the responses I'd like to hear... while (my doctor) is very supportive and helpful, she's a bit disinclined to say, "You'll still be around this time next year." (Au Patient 05)*

**Patients' sense of futility in asking questions due to spiritual perspective** – *"When they answer it precisely they get it wrong... The one thing doctors can't ever tell you for sure, when you are coming into this world and when you're going out... I think there is a point at which medicine doesn't have the ultimate answer." (US patient 12)*

Importantly, both patients and health professionals acknowledged the need to train doctors to communicate prognostic information appropriately as a crucial counterpart to the QPL.

**Training influences prognostic discussions** – *"I make it a point to bring (prognosis) up. I say we should talk about the bigger picture too. Most (patients) receive that very positively... I think the majority of oncologists might not do it that way... I think it has to do with the training" (US Health Professional 02)*

**Need to train doctors** – *"People need to be able to ask the question (about timeframes) and the doctors need to be trained on how to respond" (US Patient 16)*

## Contrasts between Australian and US feedback

Although Australian and US participants were similarly positive about the QPL, US participants seemed more ambivalent and wary of discussing the issues raised than Australian participants. US patients generally displayed more hesitation, using more euphemisms when discussing sensitive content, such as prognosis, dying or their cancer in general, while most Australian patients used more blunt language.

**US patients' use of euphemistic language** – *“You are in a hospice with a morphine drip and you just kind of drift away” (US Patient 01)*

**Australian patients' use of blunt language** – *“Well you'd like to know (what will happen) wouldn't you... you know bald, laying dead on a bed in the hall...” (Au Patient 02)*

**Australian patients' use of blunt language** – *“Preparing for the end-of-life - I thought 'this poor devil has just been told they've got a terminal disease, that's a bit heavy to throw at them...' But they have to know they've got a terminal disease... you can't sugar-coat the phrase any other way” (Au Patient 01)*

US health professionals seemed less positive than Australian health professionals about questions related to prognosis. Some indicated that unless patients specifically raised the topic, they would not necessarily discuss it.

**Australian Health Professionals more positive about prognosis** – *“I try from the word go to be realistic about prognosis and stuff so that it doesn't come as the big shock. So if a patient has metastatic disease I'm very up front from the first consultation and say, we cannot cure this. The best we can hope to do is to control it for a period of time, but it's going to get smarter than the treatment that we have.” (Au Health Professional 01)*

**US Health Professionals less positive about prognosis** – *“Any time I’m thinking that a patient needs a change in therapy or if they need an additional discussion on chemotherapy, I go through a lot of things that are relevant to the chemotherapy but try not to get into prognosis unless people ask, because it’s such an imprecise science” (US Health Professional 03)*

Additionally, some US health professionals advocated not including ACP related items due to QPL length and complexities and regional variations in US law related to this topic. They also displayed stronger opinions about which questions were more appropriately directed to other sources of information than their Australian counterparts.

**US participants’ stronger opinions about what not to ask oncologists** – *“I would say, ‘I’m not going to answer these questions (about support services) for you. We have a resource centre, my nurse knows some of these questions, and there’s a social worker” (US Health Professional 01)*

### **Final QPL text development**

Two final versions of the QPL were required to accommodate culturally appropriate language needs and contrasting Australian and US feedback regarding sensitive content. Overall, participants from both groups advocated retaining QPL content, however two items regarding treatment costs and affordability were ultimately irrelevant for the Australian QPL given the availability of public healthcare for seriously ill Australian patients, hence they were removed. The final US QPL prepared the reader with less sensitive content, reserving questions about prognosis for the fourth section in response to apparent reluctance amongst US participants to discuss that issue. Conversely, Australian participants reacted positively to these questions and they remained in the first section of

the Australian QPL. Both Australian QPLs contained questions about ACP and documenting end-of-life care preferences. These were well accepted, with patients indicating that they would be useful, prompting consideration of new issues. Some US participants suggested that end-of-life care preference documentation questions in addition to existing prognosis and timing of end-of-life discussions questions might decrease QPL acceptability and utility. Considering the positive reaction of Australian participants to this content and the importance of discussing these issues, two items regarding ACP were included in an additional section following the prognosis content in the final US QPL. Several changes were also made to the wording of various items and the introductory texts of both final QPLs in response to feedback and review by the research team. Australian and US final QPLs reflecting these developments are presented in Appendix 2.

## **Discussion**

Despite concerns that patients with advanced cancer do not want or will be distressed by prognosis and end-of-life information, [6,9] QPLs addressing these issues were well accepted by both patients and health professionals. Participants' positive responses to these QPLs suggest they could be effective tools for overcoming barriers to end-of-life discussions.

Participants highlighted various benefits of these QPLs. Patients illustrated how they could ameliorate information overload commonly experienced [30] when first informed they had incurable cancer or transitioning from curative to palliative treatment. Many wished they had received the QPL early in their disease trajectory at one of these critical moments. Several suggested such critical moments where information overload is likely were the

ideal time to introduce the QPL, adding that it could bring much needed structure to ones' communication about their care

Interestingly, while many patients were positive about the QPL content, some indicated they would delay asking certain questions. Though the point of QPL delivery is undeniably important, patients' internal determination of when to ask these questions is perhaps more influential in dictating when such discussions will occur. While we have previously highlighted the role of appropriate timing in patients' readiness for such discussions, [31] patients' decisions about appropriate timing require further investigation.

Despite recommendations that clinicians initiate these discussions, [32] our participants noted how uncertainty and collusion to remain optimistic could hinder this. [5] Most felt that the QPL could beneficially facilitate and normalise end-of-life discussions by prompting patients to raise prognosis, end-of-life issues and ACP. Importantly, several Australian and US patients indicated that the QPL had prompted consideration of new issues with some indicating that they would definitely ask those questions in the near future, particularly regarding palliative care and ACP. Consistent with previous studies, [12] our findings support the likelihood that these QPLs will promote patient involvement in consultations, supporting open communication between health professionals and patients with advanced cancer, prior to consideration of a purely palliative approach.

Though rarely mentioned, participants identified potential challenges in using these QPLs including the irrelevance, inappropriateness or futility of asking certain questions. Patients tended to consider questions irrelevant if they concerned routinely given information, including cancer type, metastasis or details of diagnostic tests; or if they were generally disinclined to ask questions during consultations. Financial concern and insurance

focussed questions were most commonly identified as inappropriate to ask oncologists, though this was more evident amongst US than Australian participants. Some patients were also ambivalent towards prognosis and end-of-life care questions, perhaps reflecting a struggle between wanting clarity and maintaining hope, a perceived dichotomy often reported by patients and health professionals. [3,6,33,34]

Some patients articulated concerns regarding the futility of asking certain questions. Several expressed beliefs that oncologists were unable to quantify ones' prognosis, hence seeking estimates had little value. Highlighting the benefits of understanding ones' prognosis whilst acknowledging known systematic prognostication inaccuracies [35] may therefore improve the worth of prognostic discussions for patients.

Other patients suggested that questions may be disregarded or answered inappropriately and that this would make using the QPL challenging. Indeed, evidence suggests QPLs are only effective when all stakeholders appropriately support their use and health professionals have the skills and willingness to communicate information accurately and compassionately. [11] Both patients and health professionals recognised the importance of communication skills, highlighting the need to train oncologists to answer prognosis and end-of-life related questions in addition to providing the QPL to patients, supporting a growing consensus regarding the importance of end-of-life communication skills training for health professionals [36] and the need to better equip oncologists to estimate and discuss life expectancy. [37] Such training has demonstrated improvements in clinician skills including estimating and framing prognostic information, responding to emotions and delivering bad news [38,39] with enduring effects in clinical settings. [40]

Participants made little mention of training patients and carers in QPL use. Nurse-led patient communication training and assistance programs for the end-of-life context, such as the SUPPORT intervention [2], have shown promise, but have been criticised for lacking concrete tools to assist with communication. This QPL could be utilised within such an intervention, giving patients and carers the opportunity to receive personalised assistance in exploring and using the QPL. Indeed, it has been suggested that communication training for patients may moderately but significantly increase their question asking [41] though evidence for training in QPL use has been less robust. [11]

The lack of enthusiasm for prognosis and end-of-life related items among some US participants relative to their Australian counterparts was surprising as previous studies have grouped Australian and US populations together as cultures in favour of medical disclosure in contrast to Europe and Asia cultures where it is less favoured. [18] Accommodating multiple populations, even as similar as Australia and the USA, when creating intervention materials containing sensitive content, such as end-of-life care, may ultimately be unfeasible, though further exploration is required. Of note were study interviewers' reports that US patients presented as less impaired by their disease than Australian patients, raising the possibility that US/Australian patient subgroup differences were related to functional status or physical wellbeing rather than cultural issues. US patient responses might conceivably have more closely resembled those of Australian patients had they been sicker. This would not account for differences between US and Australian health professionals' appraisal of some questions nor US health professionals' stronger aversion to receiving queries that could be answered by others, suggesting genuine differences between the two healthcare cultures. As no patient performance status or survival data were available, this issue deserves further exploration.

Australian QPL questions about ACP and documenting end-of-life care preferences were well accepted. Patients indicated that they would be useful and the considerable benefits afforded by ACP of allowing patients to express their preferences for future care, helping them and their carer to maintain autonomy and authority in treatment decisions once they become incapacitated are well acknowledged. [42] The initial US QPL contained no questions about documenting ACP and US participants suggested further focus on documenting end-of-life care in the context of prognosis discussions might decrease acceptability and utility. While ACP is equally important in the US, the political, social and legal climate there is somewhat polarised regarding physicians' potentially coercive role in end-of-life discussions and there is considerable variation in state laws regarding these issues. [43] However, given the value of discussing end-of-life care [44] and the likelihood that such discussions will happen over time, separate to prognostic disclosure, [45] two ACP items were included in the final US QPL.

### **Limitations and future directions**

Participants were recruited from 1 US and 2 Australian institutions. Consequently, participants' attitudes may not represent general attitudes towards end-of-life focussed QPLs. Primary tumour site did not appear to influence patients' responses, though this information was unavailable for all patients. The influence of factors such as diagnosis, age and gender on patients' attitudes and experiences cannot be ruled out and a larger sample would allow sub-group analyses to discern the impact of such variables.

All identified US patients agreed to participate, however seven Australian patients did not; one withdrew after consent believing study material to be too personal, one could not be contacted and five declined participation. Despite following stringent sampling procedures, bias introduced by enlisting oncologists to identify participants cannot be ruled out.

Patients who did not wish to discuss prognosis or end-of-life issues may also have refused participation, resulting in a biased sample.

Future studies could test the generalisability of these findings and seek the input of patients' significant others, including primary informal carers, who also participate in end-of-life discussions. Randomised controlled trial evaluation of the QPL and development and evaluation for other populations and healthcare systems is also warranted. Finally, while some participants' views on optimal timing of QPL delivery emerged during the interviews, this information was not universally available. Given the importance of timing in such discussions, [6] further investigation of appropriate delivery of an end-of-life focussed QPL is warranted.

### **Conclusion and clinical implications**

The end-of-life focussed QPL for patients with advanced cancer in the last year of life was well accepted and endorsed by patients and health professionals alike. Two versions accommodating differences in Australian and US approaches to discussions of prognosis and end-of-life issues were evaluated. This study underscores the appropriateness of tailoring communication aides and interventions, such as QPLs, to individual populations.

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### **Conflict of Interest Statement**

The authors declare that there is no conflict of interest.

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Insert Appendix 1 here

Insert Appendix 2 here

**Table 1**  
Patient demographic and disease characteristics

	Australian (n = 15 <sup>a</sup> )	US (n = 19 <sup>a</sup> )
<b>Age</b>		
Mean	67.6	58
Range	54-86	34-75
<hr/>		
	N (%)	
	Australian	US
<b>Gender</b>		
Male	12 (80)	6 (31.6)
Female	3 (20)	13 (68.4)
<b>Education</b>		
Year 10 or below/elementary/some high school	3 (20)	3 (15.8)
Year 12/HSC/GED/high school graduate	2 (13.3)	5 (26.3)
Professional qualification/some university/college	8 (53.3)	4 (21)
Undergraduate degree	1 (6.7)	5 (26.3)
Postgraduate degree	1 (6.7)	1 (5.3)
<b>Primary tumour site</b>		
Lung	9 (60)	
Bladder	1 (6.7)	
Prostate	4 (26.6)	
Kidney	1 (6.7)	
<b>Treatments received</b>		
Chemotherapy	11 (73.3)	
Radiotherapy	6 (40)	
Surgery	7 (46.7)	

<sup>a</sup> n varies due to missing data. Individual data for primary tumour site and treatments received were not collected for US patients

**Table 2**  
Health professional demographic, specialty and training characteristics

	Australian (n = 7 <sup>b</sup> )	US (n = 6 <sup>b</sup> )
<b>Age</b>		
Mean	45.3	
Range	39-50	
<b>Experience</b>		
Mean	13.3	16.5
Range	2.5-26	1-27
<hr/>		
	N (%)	
	Australian	US
<b>Gender</b>		
Male	4 (57.1)	2 (33.3)
Female	3 (42.9)	4 (66.7)
<b>Specialty</b>		
Medical Oncology	2 (28.6)	6 (100)
Radiation Oncology	1 (14.3)	0 (0)
Surgery	0 (0)	0 (0)
Nursing	4 (57.1)	0 (0)
<b>Tumour stream specialty</b>		
Lung	1 (33.3)	0 (0)
Genitourinary	2 (66.7)	1 (16.7)
Gastrointestinal	1 (33.3)	1 (16.7)
Lymphoma/Leukaemia	0 (0)	3 (50)
Brain	0 (0)	1 (16.7)
<b>Postgraduate communication training</b>		
No	4 (57.1)	4 (66.7)
Yes	3 (52.9)	2 (33.3)

<sup>b</sup> n varies due to missing data and age data was not collected from US health professionals

## Appendix 1

### Australian and US Initial Question Prompt Lists

Australian Initial Version	US Initial Version
<p><b>Title:</b> Asking questions: What now and what next...</p> <p><b>Introduction:</b> Most people who see their oncologist after treatment have questions and concerns, particularly when there are changes in their condition. Often these important questions are forgotten during a busy consultation, only to be remembered later on. The purpose of this question list is to help you to get the information that you want about your illness and what you can expect in the future.</p> <p>We have put this list of questions together after discussion with patients and their carers as well as doctors and other health care professionals. Your doctor will be happy to try to answer any questions you have now or in the future.</p> <p>You may like to circle the questions you want answered and add any of your own in the space provided. Your doctor may answer some of your questions without you even asking.</p> <p>We have organised this booklet into topics. You may find that some of these topics or some of the questions are not relevant to you at the moment. There may also be some topics or questions that you do not want to read about right now. We suggest that you read the headings first and then decide if you would like to look at the questions for each topic. Feel free to show this list to your family members.</p> <p>You can use this booklet as a checklist while you are seeing your doctor so that you can be sure that you have covered everything that is important to you.</p> <p>Different people want different things at different times. You might like to use this question list during this consultation, or at another time, or even with another member of your medical care team. You or your family may also find it helpful to refer to it in the future. Please do not feel that you have to ask any of these questions just because they are listed here.</p>	<p><b>Title:</b> Asking questions: What now and what next...</p> <p><b>Introduction:</b> To help your doctor focus on your concerns, choose the three of four questions that are most important. Ask them early in the visit. You may want to circle the question you want answered and add any of your own.</p>

Australian Initial Version	US Initial Version
<p><b>Section 1: My cancer and what to expect in the future</b></p> <ul style="list-style-type: none"> <li>• What is currently happening with my cancer?</li> <li>• What can I expect in the future?</li> <li>• Will this cancer shorten my life?</li> <li>• Is it possible to give me a time frame? How long can I expect to live?</li> <li>• What is the best-case scenario? What is the worst-case scenario?</li> </ul>	<p><b>My cancer</b></p> <ul style="list-style-type: none"> <li>• What type of cancer is it?</li> <li>• Is it local or has it spread?</li> <li>• Do I need to do any other test to find out how far it has spread?</li> </ul>
<p><b>Section 2: My treatment options</b></p> <p><i>Treating my cancer</i></p> <ul style="list-style-type: none"> <li>• What options are available to treat my cancer?</li> <li>• What are the aims of treatment for my cancer?</li> <li>• What are the pros and cons of further treatment for my cancer?</li> <li>• How likely is it that these treatments will shrink my cancer?</li> <li>• If the treatment works, will I live longer?</li> <li>• How much do these treatments cost?</li> </ul> <p><i>Treating my symptoms</i></p> <ul style="list-style-type: none"> <li>• Will these treatments make me feel better or worse?</li> <li>• Can I also have treatments to help me to feel better?</li> <li>• What options are available to control things like pain, anxiety or nausea?</li> </ul> <p><i>Palliative care</i></p> <ul style="list-style-type: none"> <li>• What is palliative care and do you think it might help me?</li> <li>• When would it be helpful for me to see someone from the palliative care team?</li> </ul>	<p><b>Treating my cancer</b></p> <ul style="list-style-type: none"> <li>• What are the aims of treatment for my cancer? <ul style="list-style-type: none"> <li>○ To cure it?</li> <li>○ To shrink it?</li> <li>○ To slow it down?</li> <li>○ To get rid of symptoms like pain?</li> </ul> </li> <li>• How can I tell if my current treatment is working?</li> <li>• How likely is it that further treatments will work?</li> <li>• Should I consider a new or experimental therapy?</li> <li>• Before deciding, are there any other professionals I should talk to? (such as other doctors or clergy)</li> </ul>
<p><b>Section 3: Making decisions about treatment</b></p> <p><i>Making a decision...</i></p> <ul style="list-style-type: none"> <li>• Should I consider stopping anti-cancer treatments now and focus more on treatments to make me feel better?</li> <li>• Is there anyone else I should talk to before making these decisions? (e.g. other doctors, organizations, websites)</li> <li>• Should I think about alternative treatments?</li> <li>• What happens if I can't afford the treatment?</li> </ul> <p><i>After I've made my decision...</i></p> <ul style="list-style-type: none"> <li>• If I decide not to have anti-cancer treatment, who will look after me?</li> <li>• If I decide not to have anti-cancer treatment, can I still see you?</li> <li>• Will you tell my GP and the other doctors looking after me about my decisions?</li> </ul>	<p><b>Treating my symptoms</b></p> <ul style="list-style-type: none"> <li>• How will further treatments make me feel?</li> <li>• Are there treatments to help me to manage pain, fatigue, nausea, or other symptoms?</li> <li>• Would it make sense for me to see a specialist in pain and symptom control?</li> </ul>

Australian Initial Version	US Initial Version
<p><b>Section 4: My life, my family and making plans</b></p> <ul style="list-style-type: none"> <li>• How can I make the most of my life, living with this cancer?</li> <li>• Are there any lifestyle changes that may help me make the most of my life, living with this cancer? (e.g. diet, exercise)</li> <li>• What can I expect to be able to do in the future? (e.g. working, driving, holidays)</li> </ul>	<p><b>What I can expect</b></p> <ul style="list-style-type: none"> <li>• What can I expect to be able to do in the future? (e.g. working, driving, travelling, holidays)</li> <li>• Will this cancer shorten my life?</li> <li>• Is it possible to give me a time frame?</li> <li>• What is the best-case scenario?</li> <li>• What is the worst-case scenario?</li> </ul>
<p><b>Section 5: Support for me and my family</b></p> <p><i>Support for me</i></p> <ul style="list-style-type: none"> <li>• What support is available for me?</li> <li>• What information is available about my future care and what is happening to me? (e.g. books, videos, pamphlets)</li> <li>• Are there any organizations or services that would be useful for my carer or me to contact? (e.g. support organizations, respite care, disability parking)</li> <li>• What financial assistance is available for my carer or me?</li> <li>• Who can I talk to about my spiritual, religious and emotional needs?</li> </ul> <p><i>Support for my family</i></p> <ul style="list-style-type: none"> <li>• How can I help my family and children understand what is happening? Can someone help me to do this?</li> <li>• What support is available now and in the future for my carer, my children and my family?</li> <li>• What should I do if members of my family disagree about my decisions?</li> </ul>	<p><b>What I can do</b></p> <ul style="list-style-type: none"> <li>• What can help me get the most out of my life (eg, diet, exercise, meditation, massage, support groups, etc.)?</li> <li>• Are there any specific materials patients like me have found useful (eg, books, videos, pamphlets)?</li> <li>• Are there any organizations or services that would be useful for me or my caregiver (such as support organizations, social services, disability parking)?</li> </ul>
<p><b>Section 6: Preparing for the end of life</b></p> <ul style="list-style-type: none"> <li>• Who can I talk to about preparing for the end of life?</li> <li>• Is there a way to document my wishes for care at the end of life?</li> <li>• Should I appoint someone to make medical decisions on my behalf in case of emergency situations or if I am too unwell to speak for myself?</li> <li>• Is there anything I need to do to make these arrangements official?</li> <li>• How can I make sure that others involved in my care know my wishes?</li> <li>• What can I do to sort out my personal matters and write my will?</li> </ul>	<p><b>If treatment doesn't work</b></p> <ul style="list-style-type: none"> <li>• Who will be my doctor if I stop getting chemotherapy or radiation?</li> <li>• What is... <ul style="list-style-type: none"> <li>○ Palliative care?</li> <li>○ Hospice?</li> <li>○ What is the difference?</li> </ul> </li> <li>• How will I know if I need to talk about the end of life?</li> <li>• What will likely happen at the very end? Will I be in a lot of pain or other discomfort?</li> </ul>

Australian Initial Version	US Initial Version
<p><b>Section 7: Other questions your family and/or carer may like to ask</b></p> <ul style="list-style-type: none"> <li>• What skills will I need to support the person I am caring for?</li> <li>• What can I do to look after myself whilst caring for my partner/relative/friend?</li> <li>• Who can I talk to if I am concerned about the care my partner/relative/friend is receiving?</li> <li>• What help can I get if I can't cope with caring for my partner/relative/friend?</li> </ul>	<p><b>Concerns of family members and/or caregivers</b></p> <ul style="list-style-type: none"> <li>• How can I help my family and children understand what is happening? Can someone help me do this?</li> <li>• What skills will they need to help take care of me?</li> <li>• What can they do to cope and care for themselves while caring for me?</li> <li>• Who can they talk to if they are concerned about me or my care?</li> </ul>

## Appendix 2

### Australian and US Final Question Prompt Lists

Australian Final Version	US Final Version
<p><b>Title:</b> Conversations with your doctor: Discussing your care as cancer progresses – a list of useful questions</p> <p><i>Introduction - Asking Questions: What Now and What Next...</i></p> <p>Getting information about what is currently happening with your cancer and what you can expect in the future can be challenging. Most people have concerns they wish to raise with their oncologist, particularly when there are changes in their condition. It can be difficult, however, to work out what questions to ask. Often these important questions are forgotten during a busy consultation, only to be remembered later on.</p> <p>Thinking about the questions you would like to ask your oncologist and writing them down before the consultation can be extremely helpful. To assist with this, we have listed some of the questions that patients, carers and health professionals have found useful in a situation similar to yours.</p> <p>We have divided the questions into topics, some of which may be more relevant to you now and others more relevant to you later. You can ask the questions word for word or use them as a checklist of things you want to find out. We suggest that you read through all of the questions and tick the ones you think you would like to ask now. There is also space on each page for you to add your own questions or notes.</p> <p>It may be helpful for you to prioritise your questions, as you may not get to ask them all at once and some may be more important to you than others. Also, feel free to share this list with your family members or friends; they may have questions of their own.</p> <p>You might like to use this list of questions during your next oncology consultation, at a later time, or even with another member of your health care team. Your questions and concerns can help your oncologist understand what your priorities are and work out what is best for you. He or she will be happy to try to answer any questions you have at any stage and may even answer some of your questions without you even asking.</p> <p>We encourage you to communicate your questions and concerns to your oncologist and health care team. Please do not feel, though, that you have to ask and of these questions just because we have listed them here.</p>	<p><b>Title:</b> Asking questions: What now and what next</p> <p><i>Introduction</i></p> <p>Most people who see their oncologist have questions and concerns. It's very common to forget important questions during an office visit, only to wish you had remembered to ask them later on.</p> <p>This booklet can help you to get the information you want about your cancer and what you can expect in the future.</p> <p>We put this list of questions together after discussion with patients, their families and their caregivers as well as doctors and other health care professionals. These questions can help your doctor to answer any questions you have now or in the future.</p> <p><i>How to use this booklet</i></p> <p>We have organized this booklet into topics. You may find that some of these topics or questions are not relevant to you at the moment. There may also be some topics or questions you do not want to think about right now. Read the headings first and then decide if you would like to look at the questions for each topic.</p> <p>Feel free to show this list to your family. They might find it helpful, too.</p> <p><i>Remember that time is limited, so pick the questions that are the most important to you.</i></p> <p>You might like to use this question list during this office visit, or at another time, or even with another member of your medical care team.</p> <p>You or your family may also find it helpful to refer to it in the future. Different people want different things at different times. Please do not feel that you have to ask any of these questions just because they are listed here.</p>

Australian Final Version	US Final Version
<p><b>Section 1: My cancer and what to expect in the future</b></p> <ul style="list-style-type: none"> <li>• What is currently happening with my cancer?</li> <li>• What can I expect in the future?</li> <li>• Will this cancer shorten my life?</li> <li>• Is it possible to give me a time frame? How long can I expect to live?</li> <li>• What is the best-case scenario? What is the worst-case scenario?</li> </ul>	<p><b>My cancer</b></p> <ul style="list-style-type: none"> <li>• What kind of cancer do I have?</li> <li>• What is currently happening with my cancer?</li> <li>• What are the main aims of treatment for my cancer? <ul style="list-style-type: none"> <li>○ To help me live longer (slow the cancer, remission or cure)?</li> <li>○ To improve quality of life and improve symptoms (like pain)?</li> </ul> </li> <li>• Is it still possible to cure my cancer?</li> </ul>
<p><b>Section 2: Treating my cancer</b></p> <ul style="list-style-type: none"> <li>• What options are available to treat my cancer?</li> <li>• What are the pros and cons of further treatment for my cancer?</li> <li>• Is it still possible to cure my cancer?</li> <li>• How likely is it that these treatments will control my cancer?</li> <li>• If the treatment works, will I live longer?</li> <li>• Will these treatments make me feel better or worse?</li> </ul>	<p><b>Treating my cancer</b></p> <ul style="list-style-type: none"> <li>• What are the benefits and side effects of further treatment for my cancer?</li> <li>• How likely is it that the cancer treatments will make me feel better? Control my cancer? Live longer?</li> <li>• How will I know that treatment is working?</li> <li>• Are treatments covered by insurance?</li> </ul>
<p><b>Section 3: Palliative Care</b></p> <ul style="list-style-type: none"> <li>• What options are available to control things like pain, anxiety or nausea?</li> <li>• What is palliative care and do you think it might help me?</li> <li>• When would it be helpful for me to see someone from the palliative care team?</li> </ul>	<p><b>Treating my symptoms</b></p> <ul style="list-style-type: none"> <li>• What treatments can help me manage my symptoms? <ul style="list-style-type: none"> <li>○ Pain</li> <li>○ Nausea, diarrhoea</li> <li>○ Fatigue</li> <li>○ Depression, anxiety</li> <li>○ Other symptoms?</li> </ul> </li> <li>• How long might these treatments take to work?</li> <li>• Would it make sense for me to see a specialist in pain and symptoms control (such as palliative care or pain clinic)?</li> </ul>
<p><b>Section 4: Making a decision...</b></p> <ul style="list-style-type: none"> <li>• Should I consider stopping anti-cancer treatments now and focus more on treatments to make me feel better?</li> <li>• Is there anyone else I should talk to before making these decisions? (e.g. other doctors, organizations, websites)</li> <li>• Will you tell my GP and the other doctors looking after me about my decisions?</li> </ul>	<p><b>What I can expect</b></p> <ul style="list-style-type: none"> <li>• What can I expect to be able to do in the future? (e.g. working, driving, travelling, holidays)</li> <li>• Will this cancer shorten my life?</li> <li>• Is it possible to give me a time frame?</li> <li>• What is the best-case scenario? The worst-case scenario?</li> <li>• What is likely to happen at the very end? How could I prepare for that time?</li> </ul>
<p><b>Section 5: My lifestyle</b></p> <ul style="list-style-type: none"> <li>• Are there any lifestyle changes that may help me make the most of my life, living with this cancer? (e.g. diet, exercise)</li> <li>• What can I expect to be able to do in the future? (e.g. working, driving, holidays)</li> </ul>	<p><b>Preparing for the future</b></p> <ul style="list-style-type: none"> <li>• How can I be sure that my family and my physicians know my wishes about treatments in case I am unable to decide for myself?</li> <li>• Should I complete a health care proxy and/or living will form?</li> </ul>

Australian Final Version	US Final Version
<p><b>Section 6: Support for me</b></p> <ul style="list-style-type: none"> <li>• If I decide not to have anti-cancer treatment, who will look after me?</li> <li>• If I decide not to have anti-cancer treatment, can I still see you?</li> <li>• What other support is available for me?</li> <li>• What information is available about my future care and what is happening to me? (e.g. books, videos, pamphlets)</li> <li>• Are there any organisations or services that would be useful for my carer or me to contact? (e.g. support organisations, respite care, disability parking)</li> <li>• What financial assistance is available for my carer or me?</li> <li>• Who can I talk to about my spiritual, religious and emotional needs?</li> </ul>	<p><b>What I can do</b>  <i>Sometimes a nurse, social worker, physical therapist, or nutritionist might be able to help you with these questions *(marked with an asterisk):</i></p> <ul style="list-style-type: none"> <li>* What can help me feel better? (e.g. diet, exercise, meditation, massage, support groups, etc.)</li> <li>* Are there any therapies you think I should stay away from?</li> <li>* How can I learn more? (e.g. books, videos, pamphlets)</li> <li>* Are there any organizations or services that would be useful for me or my caregiver? (e.g. support organizations, social services, disability parking)</li> </ul>
<p><b>Section 7: Support for my family</b></p> <ul style="list-style-type: none"> <li>• How can I help my family and children understand what is happening? Can someone help me to do this?</li> <li>• What support is available now and in the future for my carer, my children and my family?</li> <li>• What should I do if members of my family disagree about my decisions?</li> </ul>	<p><b>If cancer treatment isn't working</b></p> <ul style="list-style-type: none"> <li>• Should I consider stopping anti-cancer treatments and focus more on treatments to make me feel better?</li> <li>• Should I consider experimental therapy or clinical trial? A second opinion?</li> <li>• Who will be my doctor if I stop getting chemotherapy or radiation?</li> <li>• What is hospice? How will I know when I might need to consider hospice?</li> </ul>
<p><b>Section 8: Making sure my wishes are honoured</b></p> <ul style="list-style-type: none"> <li>• Is there a way to plan and document my wishes for care at the end of life?</li> <li>• If my wishes change, how do I make sure people know and respect that?</li> <li>• Should I appoint someone to make medical decisions on my behalf in case of emergency situations or if I am too unwell to speak for myself?</li> <li>• Is there anything I need to do to make these arrangements official?</li> <li>• How can I make sure that others involved in my care know my wishes?</li> </ul>	<p><b>Your family might like to ask</b></p> <ul style="list-style-type: none"> <li>• How can I help my family and children understand what is happening? Can someone help me do this?</li> <li>• What skills will I need to care for my family member with cancer?</li> <li>• Are there reading materials for me?</li> <li>• Who can I talk to if I am concerned about my loved one's care?</li> </ul>
<p><b>Section 9: Other questions your family, friends or carer may like to ask</b></p> <ul style="list-style-type: none"> <li>• What skills will I need to support the person I am caring for?</li> <li>• What can I do to look after myself whilst caring for my partner/relative/friend?</li> <li>• Who can I talk to if I am concerned about the care my partner/relative/friend is receiving?</li> <li>• What help can I get if I can't cope with caring for my partner/relative/friend?</li> </ul>	<p><b>Remember...</b>  <b>To help your doctor focus on your concerns:</b></p> <ul style="list-style-type: none"> <li>• Bring this booklet with you to your appointments</li> <li>• Because time is limited, circle 3 or 4 questions that re the most important to you for any one visit</li> <li>• Write down other questions you might have</li> <li>• Ask questions early in the visit to make sure that your doctor has time</li> </ul> <p><i>You can use this booklet as a checklist while you are seeing your doctor so you can be sure you have covered the most important questions to you and your family.</i></p>