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A Systematic Literature Review on Question Prompt Lists in Health Care: Final Report

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ahsri
australian health services
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UNIVERSITY OF
WOLLONGONG

Jan Sansoni

Pam Grootemaat

Cathy Duncan

Peter Samsa

Kathy Eagar

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Contents

List of Tables

1 Executive Summary

This review of the evidence concerning the use of Question Prompt Lists was commissioned by the Australian Commission on Safety and Quality in Health Care. This rapid, but systematic review, using best practice synthesis has examined the evidence concerning the use of Question Prompt Lists and Patient Question Prompt Lists as communication aids to enhance patient question asking and patient participation in health and medical consultations. Question Prompt Lists can be a prepared list of questions provided to the patient by the care team, where the patient selects those questions they wish to ask the doctor (QPL). Alternatively, there can be patient question prompt lists (PQPL) that the patient generates prior to the consultation following a request or prompt to do so. Sometimes a health card may be provided which has a list of topics the patient might consider or a patient agenda form.

A comprehensive research strategy was implemented to identify both the academic and grey literature, using search terms such as question prompt list or sheet, patient questions, question asking and asking questions, shared decision-making, patient decision making, patient decision aids, clinical decision support tools and interventions and physician/patient relationship. These terms were used to search academic databases such as Medline, Psychinfo, Cinahl, Scopus, Proquest and Cochrane Collaboration as well as search engines such as Google to identify relevant material for the review. Other search techniques, such as snowballing were also used to identify relevant literature.

This search strategy detected a large number of articles (199) concerning PQPL and QPL studies including intervention/experimental studies as well as those that concern acceptability and usability evaluations.

The following categorisation of studies has been applied to the review of this literature:

- Single and multiple intervention studies: (The results of patients who received a QPL/PQPL to use in the consultation are compared with ‘control’ patients who did not receive a QPL/PQPL; or this, plus additional intervention groups such as those who receive coaching in question asking as well as a QPL/PQPL)
- Combined intervention studies (e.g. coaching plus QPL/PQPL group compared with a control group)
- Studies concerning the acceptability and usability of a PQPL or QPL (patient and clinical feedback; pilot-testing)
- Systematic literature reviews and literature summaries
- General background literature (e.g. concerning question asking, patient participation more broadly and patient preferences in relation to shared decision making and participation) and
- Grey literature that may reflect on QPL/PQPL resources available on the internet and also reflect upon their current use in routine care

The findings from these different sources of literature have been summarised and reviewed. A rating of the strength of evidence has been applied to the research studies reviewed (see Section 3). In this review the evidence concerning the most commonly measured outcomes has been assessed. These include such elements as the effect on patient total question asking, question asking by content area, and the provision of information by the doctor; patient knowledge recall; anxiety; patient satisfaction and total consultation time. Only a few

QPL/PQPL studies have examined other issues such as patient decision making or communication preferences and the perceived decision making role of the patient.

Overall the literature suggests that research on the effectiveness of QPL and PQPL interventions is still at a relatively early stage, with only suggestive rather than clear and definitive findings. There is reasonable evidence that an appropriately designed and relevant QPL/PQPL, that is actively endorsed by the physician, and provided immediately before the health consultation, may increase patient question asking in consultations, and may lead to more information being provided by the doctor in these consultations.

A key issue appears to be whether the doctor actively endorses the QPL/PQPL. The degree of doctor endorsement can vary from the provision of a QPL/PQPL for the patient to use as they wish, encouragement to hand the QPL/PQPL to the doctor, the provision of coaching/training in question asking by a member of the medical team through to ensuring the doctor receives and addresses the QPL/PQPL. Papers that have shown an increase in total question asking by the patient are usually actively endorsed; the question list is given to the doctor at the beginning of the consultation and the doctor addresses the issues the patient has identified (Brown et al., 1999; Clayton et al., 2007; Middleton et al., 2006; Smets et al., 2012: although note that Brown et al., 2001 did not find a difference). When the QPL/PQPL is not actively endorsed there have been inconsistent findings with respect to total question asking with quite a number of studies reporting no increase in total questions asked. As discussed in the body of the report it is suspected that measurement methods may also impinge on some of these findings.

The majority of single or multiple intervention studies (with varying degrees of doctor endorsement) have also reported finding a small but significant increase in questions about diagnosis, prognosis and treatment aspects when a QPL/PQPL has been used (Brown et al., 1999; Brown et al., 2001; Bruera et al., 2003; Butow et al., 1994; Clayton et al., 2007; Fleissig et al., 1999; Smets et al., 2012.) although a study by Shirai et al. (2012) found no increase. For combined intervention only two studies examined this issue and they both had significant findings (Roter, 1984; Van Weert et al 2011).

Only a few single intervention QPL studies have investigated the amount of information provided by the doctor, (from audio-tape analysis of the consultation) but these studies suggest the amount of information provided is significantly increased (Clayton et al., 2007; Hornberger et al., 1997; Shepherd et al., 2011) and similar findings are reported for combined intervention studies.

There were no consistent findings concerning a significant effect on knowledge recall, anxiety and patient satisfaction but these are complex variables which can interact with each other (e.g. anxiety reduction has been associated with an increase in patient satisfaction across all patient groups; Lim et al. 2011). However, given the few significant findings concerning anxiety, it appears that any unintended adverse effect associated with anxiety and QPL use is unlikely.

Methodological issues have been raised concerning the assessment of knowledge recall in QPL intervention studies as there are varying periods for knowledge recall used across the studies and memory may vary across time. The appropriateness and the validity of some of the measures used have also been questioned (van der Meulen et al., 2008; Watson et al., 2009).

Overall half the studies examined showed no significant effects for patient satisfaction, however, it is known that most patients, regardless of group, report high levels of satisfaction on these instruments (known as ceiling effects; Hawthorne, 2006). This makes it difficult to detect intervention effects. A few studies examined the perceived decision making role of the patient in relation to patient satisfaction. Gattellari et al. (2001) found that patient retrospective reports of a shared decision making role in the consultation were associated with greater patient satisfaction although Singh et al., (2010) suggests there may be an interaction between the preferred patient decision making role, the presence of doctor SDM behaviours, and patient satisfaction.

Further research is required to investigate the variables of anxiety, knowledge recall and patient satisfaction; the potential interaction effects between these factors and to identify more sensitive and valid measurement tools for the assessment of these domains.

It should be noted that the effect of these interventions on consultation length is still unclear as the findings are not consistent although many studies report no increase in consultation time. However, the evidence suggests that when patient question asking and participation is increased by the intervention then there may be an associated small increase in consultation time (Clayton et al., 2007; Eggly et al., 2006; Hornberger et al., 1997; Middleton et al., 2006). The intervention time for single intervention studies is likely to be quite short, but is rarely stated, and cost estimates for routine implementation would need to take the time for the implementation of a PQPL/QPL into account.

The majority of studies have examined the use of a QPL in medical specialties (particularly cancer) and fewer studies have examined the use of PQPL and QPL strategies in general practice settings. Some studies (Cegala et al., 2000; Hornberger et al., 1997; Roter 1977, Roter 1982; Middleton et al., 2006) have reported some positive findings with respect to the effectiveness of the QPL/PQPL in increasing question asking or issues identification in these settings. Other studies such as Tennsted et al. (2000) and Wetzels et al. (2005) found problems with low use of the QPL/topic list by elderly patients who were sent the materials some time prior to the health visit. Concerning the use of a QPL in general practice, given the diversity of the consultations concerned, there may be difficulties in designing a QPL that is relevant to the majority of patients unless the questions are fairly generic. Most of these studies made use of a PQPL. A more recent approach is to suggests three generic questions for patients to ask (Galliher et al., 2010; Shepherd et al., 2011; King et al., 2013), but there is little evidence available as yet concerning the effectiveness of this approach and caution is advised concerning its adoption until the evidence is more substantial.

There is a wealth of evidence (see Table 5) that reports that most patients find using a QPL/PQPL helpful which supports the notion that when QPL/PQPLs are used they are perceived as useful by patients in both helping them to frame questions and in enhancing the consultation.

Given the above there is probably sufficient evidence to support further trials and use in routine practice. It is recommended it may be best to start with medical specialty areas where an appropriately designed and tested PQPL/QPL may be available. If so, careful consideration should be given to the findings of Dimoska et al. (2012) that recently examined a routine practice trial in cancer settings in Australia. Dimoska et al. (2012) identified a range of factors which can facilitate implementation which included the promotion by clinical champions, negotiation with the clinics concerning dissemination methods, and strategies to raise both patient and physician awareness.

In considering such initiatives consideration should be given to the fact that the evidence from this review and others suggests that only up to 50% of patients' (Albada et al., 2011; Cunningham et al., 2000; Dimoska et al, 2012, Jones et al., 2002; Volz et al., 2013) may make use of a QPL/ PQPL if offered one. Given this some analysis of the cost effectiveness, or the estimated return on investment, of such initiatives could be considered. Other cost factors to be considered also include the development and testing of a QPL/PQPL if one is not available. Cost estimates for routine implementation would need to take the time for the implementation of a PQPL/QPL into account and any effect such as an estimated small increase in consultation time. As well there would be costs involved in suggested strategies to enhance clinician and patient awareness of the approach and costs for clinical training. There is little cost data available as yet as most studies have only focussed on consultation time and have not considered implementation and development costs and thus more information on the costs associated with routine implementation are required.

Patient feedback and the recent study by Dimoska et al. (2012) also suggest it is best to provide the QPL to new patients when first diagnosed or at the beginning of a particular phase of treatment (e.g. radiotherapy, chemotherapy) rather than to those who are midway through a phase of treatment. Our recommendation is that the QPL should also be given immediately prior to the consultation. Studies where the material has been sent to patients a week or more before the consultation report low usage rates as patients forget to bring the materials to the consultation (Bolman et al., 2005; Martinali et al., 2001; Tennsted, 2000; Wenzels et al., 2005). Shepherd and Tattersall (2011) and Dimoska et al. (2008) suggested sending an information pack to patients before the consultation to give them more time to consider the QPL, but unless this is within two days prior to the consultation (as was the case with Butow et al., 1994), the evidence from this review would suggest this strategy is not advised.

While most studies examine the use of a QPL/PQPL in research settings, Dimoska et al. (2012) examined their routine implementation for medical and radiology consultations in Sydney with promising results. Another example from the 'grey' literature is the implementation of the 'Ask Three Questions' initiative, as part of the MAGIC program concerning the implementation of a shared decision making approach to health and medical consultations in the UK. Both of these evaluations indicate the introduction of a communication aid such as the QPL needs to be accompanied by training of health workers and media initiatives to increase awareness of both patients and health professionals about the approach.

Findings from the 'grey' literature have indicated that the use of QPLs is most prevalent in the USA and in cancer and palliative care clinical settings in Australia although the 'Ask Three Questions' NHS initiative is currently being evaluated in the UK. A number of QPL internet resources are provided by the Cancer Institute of NSW. However, many web sites present QPLs as tools for use by patients or doctors without any supporting evidence concerning their development and use. It is suggested that this background information should be included on web-sites where QPLs are presented.

Some studies have investigated the use of computer-generated individualised question lists, usually in combination with an education package. The Agency for Healthcare Research and Quality in the US has provided a website where a patient can build their own PQPL for their next consultation. Although not all patients will have access to the internet or be as adept at using it, these strategies also warrant further investigation.

This review has also identified a range of research gaps that need to be further addressed. These include strategies to determine the optimum length of a QPL and the tailoring of question lists for those from other cultural backgrounds and for special needs groups. These issues are discussed in the conclusion and in the body of the report.

In conclusion it is noted that while a QPL/PQPL has the potential to enhance medical consultations, QPLs in isolation, however, are not a substitute for effective communication and cannot 'fix' poor communication between doctors and patients. It should also be remembered that patient question asking is only a relatively small component of communication within a health consultation. More recent studies which examine patient preferences for participation in decision making during consultations indicate that patient's communication and decision making preferences vary and thus there is the need for the doctor to individualise their communication style to address these preferences (Brom et al., 2014; Rodin et al., 2009) The development of effective communication skills and the appropriate use of communication aids by health workers needs to be addressed through clinical training and other peer led strategies. Patient understanding and awareness of the approach also needs to be facilitated as part of any implementation in routine care.

2 Introduction

This review concerns the effectiveness of Question Prompt Lists (QPL) and Patient Question Prompt Lists for use by consumers, clinicians and health care services. Question Prompt Lists can be a prepared list of questions provided to the patient, where the patient identifies those questions they wish to ask the doctor/health professional (QPL). Alternatively, there can be patient question prompt lists (PQPL) that the patient generates prior to the consultation following a request or prompt to do so. Sometimes a health card or patient agenda form may be provided which has a list of topics or concerns that the patient might consider. The purpose of a QPL/PQPL is to provide patients with clearer information concerning their treatment and to address any concerns they may have; to enhance the communication between the patient/consumer and the treating clinician, to promote patient participation and to potentially enhance shared decision making within the health consultation.

2.1 Context

Central to the philosophies of evidence based health care and the health outcomes approach is that patients should be provided with information about the alternative treatments for their health condition to allow for their informed consent and to provide them with the opportunity to participate in decision making concerning their health condition (Sansoni, 2007; Glasziou and Del Mar, 2003).

As an outgrowth from these approaches there is currently much interest in adopting Shared Decision Making (SDM) practices and in the provision of Patient-Centred Health Care. Patient-centredness is a core aspiration of health care as it may enable patients to align the care they get with the care they want and it espouses a practice built on the respect for patient preferences and a productive patient-clinician relationship (Ferrer and Gill, 2013). Increasingly it is recognised there is a need to foster and recognise the importance of patient-centred care and participation.

Shepherd et al. (2011) note that patients need tailored information from their health care professionals about treatment and test options, including their risks and benefits and the likelihood of these occurring in order to achieve informed consent and to make informed health care decisions. They note that provision of reliable and accurate information is part of high quality patient centred care, it promotes evidence based practice, it may improve both the experience and outcomes of care and has been endorsed in patient charters. These authors identified three key questions for patients to ask during their consultations which have since been incorporated in the NHS Health Foundation Making Good Decisions In Collaboration (MAGIC) program (King et al., 2013;).

One aspect/sign of patient-centred health care is that health care choices are made through shared decision making. SDM involves a process where the patient and the clinician work together to integrate the patient’s concerns, values and goals with the best available evidence about benefits, risks and uncertainties of treatment in order to make appropriate health care decisions (Legaré, 2013; Marshall and Buchan, 2013). SDM makes use of many methods to achieve the implementation of SDM (such as clinician and patient education; King et al., 2013) and of a variety of tools and aids (communication aids, decision support aids, patient decision making aids) have also been designed to help accomplish this task.

Bouleac et al. (2010) stressed the need for a patient-centred communication strategy for health and medical consultations including the discussion of treatment options and patient outcomes. The inadequacy of patient information concerning treatment has been raised previously by Craft et al (2005) and Tattersall (2002) amongst many others. Bouleac et al. (2010) identified that communication and patient-centredness can be facilitated by examination of patient quality of life issues and by the use of patient information and decision support tools. One of the simplest of these approaches is to use communication aids such as a question prompt list to enhance the information that a patient receives from a consultation.

2.2 Patient Question Lists

Thus there is a growing research literature concerning the use of Question Prompt Lists (QPL) as one method to enhance the communication between the patient/consumer and the treating clinician. Earlier systematic reviews related to shared decision making and the use of communication aids (including some QPL studies) suggested a small but significant increase in patient question asking (Kinnersley et al., 2007), a positive effect on recall of medical information and an increase in patient knowledge (van der Muelen et al., 2008) and an increase in provision of information about prognosis (Gaston et al., 2005).

There are also recent health system level initiatives/campaigns to include QPLs or ‘Three Questions to Ask your Doctor’ in the National Health Service of the United Kingdom. This initiative is within the context of a broader program (MAGIC) to foster shared decision making and which also examines a range of other decision making aids and strategies such as option grids or brief decision aids (King et al., 2013). The Agency for Healthcare Research and Quality in the United States of America also has a ‘Questions to Ask Your Doctor’ initiative (AHRQ, 2012). In Australia QPLs have been developed, in particular, for use in cancer care (Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), Cancer Institute, NSW) and for asthma care (Asthma Australia, 2014). The School of Public Health, Queensland University of Technology has worked on the ‘It’s okay to ask’ resource for people with a brain tumour. CeMPED also worked with Australian Cancer Trials (Cancer Australia) on two QPLs for cancer clinical trials.

As Brown et al. (1999) noted if a QPL can be shown to be effective then it becomes a simple, inexpensive and effective means of enhancing patient question asking and participation in the consultation. The use of a QPL also aligns well with more recent and broader initiatives to enhance shared decision making in health and medical consultations (King et al., 2013).

2.3 Outline of the Review

This review examines the effects of QPL use on outcomes such as patient participation in the consultation, including question asking. It examines the effects on other outcomes such as increased knowledge recall, enhancing treatment choices and patient satisfaction. Any adverse or unintended effect associated with QPL use, such as increased patient anxiety, is also examined. Issues concerning QPL implementation in routine care are addressed, including factors that affect QPL uptake and effectiveness. Factors which pertain to the costs of implementation, such as the effects on consultation duration, are also considered.

A systematic search of the research literature has been undertaken (see Section 3 identified approximately 99 articles addressing the use of a QPL/PQPL in particular (Table 1 - Table 6). Searches also identified some more general literature (53 articles) and ‘grey’ (not academically published) literature (47 articles) relating to the use of communication and decision support aids and patient question asking in relation to shared decision making. The general literature provides a broader context for the use of the QPL and in some instances has identified issues and research gaps that may be addressed in the future (Appendix 1). The research literature is reviewed in Section 4.

Searches of the research literature have been supplemented by an examination of the grey literature (e.g. relevant health department reports) and Australian and international websites to reflect on the use of QPLs in routine practice (Section 5)

The conclusion (Section 6) addresses the following issues:

- What evidence is there concerning the effectiveness of the QPL? Is there sufficient evidence to promote their more widespread application in routine care?
- What factors influence the effectiveness of a QPL (e.g. doctor endorsement)?
- What are the requirements for the effective implementation of Question Prompt Lists across a range of conditions and different care settings?
- What are the key research issues which require further investigation?

3 Literature Search Strategy and Methodology

The literature review methodology and search strategy has included the following elements:

3.1 Identification of Available Published Literature (peer reviewed)

The following strategies have been applied to identify published literature:

- Search of relevant bibliographic databases using Summon, including Medline, Psychinfo, Cinahl, Scopus, Proquest and Cochrane Collaboration for original contributions and review papers. In addition, in-depth searches of relevant databases as suggested by Summon have been conducted.
- Using “snowballing” techniques including scanning references, using Google Scholar to identify citations and searching by key authors in the field.
- Electronic searching of web based materials including identification of government studies, and reports, relevant review articles, and electronic citation searches.

Search terms have included such elements as question prompt list, question prompt sheet, patient questions, question asking and asking questions. Secondary search terms were added to broaden the search including shared decision-making, patient decision aids, clinical decision support tools/interventions, physician/patient relationship and ‘decision making, patient’. A detailed outline of the search strategy appears in Appendix 2.

Where peer-reviewed research evidence is available, the literature review has included a summary of the key features of each study (e.g. research purpose, design, methods, findings and any identified problems with the study).

A total of 293 documents were identified for possible inclusion in the review. Two staff then independently rated the remaining abstracts for their relevance and 241 papers including grey literature documents were identified and retrieved for potential inclusion in the review. Some research articles retrieved were found to be of marginal or limited relevance upon reading (42 articles) and were then rejected for inclusion in the review. Summaries of 152 research articles and 47 grey literature articles were completed.

3.2 Identification of Other Published Literature (non-peer reviewed material)

Strategies for obtaining relevant research from the ‘grey’ or practice literature via the internet have included the searching of grey literature electronic databases. The latter included the searching of relevant State and National Health Department sites, relevant health quality and safety conference sites, international health care and evidence based health care sites and Australian organisations concerned with patient safety and quality and health services research.

- Reports and articles available on the internet were identified through search engines such as Google (advanced), Google (scholar) and Summon (UOW search engine - also includes grey literature).
- Authors who presented abstracts on relevant topics during national and international conferences formed the basis for some additional author-based searches.
- Other Australian experts involved in the development and implementation of question prompt lists related to shared decision-making initiatives were contacted where possible, particularly with reference to the application of QPLs in routine care.

For material relevant to the topic that is not peer-reviewed research, the literature review includes a summary of information relevant to the key issues and questions of interest.

3.3 Inclusion and Exclusion Criteria

Australian and international published peer reviewed literature regarding the use of question prompt lists in relation to shared decision-making in health and medical consultations.

Literature published from the year 2000 to the present and that is written in English.

Material from the last fourteen years is of primary interest to the literature review. However, where information from earlier literature is identified, particularly through systematic literature reviews, this literature has been included.

Although there is a broader literature relating to clinical decision-making best practice by health care practitioners this literature will be largely excluded as the literature review will focus on the use of question prompt lists as a communication/information aid. Given this, it has not been our intention to cover all the literature related to shared decision making and/or patient decision aids although some of the broader literature has been included to provide a context for the use of QPLs as an initiative within the broader field of shared decision making.

3.4 Methodology

The literature has been reviewed and classified based on the criteria as set out below.

3.4.1 Strength of Evidence

1. **Well-supported practice** – evaluated with a controlled trial (including cluster control) and reported in a peer-reviewed publication with no major design flaws evident*
2. **Supported practice** – evaluated with a controlled trial group and reported in a government report or similar*; systematic literature review including meta-analysis
3. **Promising practice** – evaluated with a comparison to another comparable health system or service; systematic literature review supported by a systematic search strategy
4. **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (e.g., pre- and post- comparisons, post-reporting only or qualitative methods)
5. **Emerging practice** – evaluated without an independent assessment of outcomes (e.g., formative evaluation, qualitative evaluation conducted internally; reviews of key articles not supported by a systematic search strategy)
6. **Routine practice** (e.g., analysis of routine data)
7. **Expert opinion** (e.g., peak bodies, government policy, individual opinion pieces)
8. **Case-Study** (e.g. one-shot case studies or a group of case-studies that are largely anecdotal
9. **Other** (e.g. psychometric analyses, economic evaluations and service utilisation studies)

* Where a controlled trial has design or implementation issues this will be noted and the strength of evidence classification will be lessened.

3.4.2 Relevance Criteria

Significance of effects are summarised in both the literature overviews for each type of study and in the associated article overviews and the tables provided. The significance levels of the major findings are reported. The country of origin is specified in the literature overviews and issues pertaining to applicability to Australia are reported in the text where appropriate.

3.4.3 Research Literature Classification

Literature overviews have been provided by the type of study. The following categorisation of studies has been applied to the review of this literature:

- Single and multiple intervention studies
- Combined intervention studies

- Studies concerning the acceptability and usability of a PQPL or QPL
- Systematic literature reviews and literature summaries
- General background literature (e.g. concerning question asking, patient participation more broadly and patient preferences in relation to shared decision making and participation) and
- Grey literature that may reflect on QPL/PQPL resources available on the internet and also reflect upon their current use in routine care

Although the searches detected numerous articles which mention the use of a QPL, describe their development, or discuss usability aspects (Table 5, Appendix 1), relatively few articles were found that actually assess the effectiveness of either patient generated question lists (PQPL) or research prepared question lists, such as a QPL, (which usually relate to a particular health condition/type of treatment e.g. chemotherapy). In reviewing this literature we will focus firstly on literature concerning PQPL/QPL interventions. This will be followed by an examination of studies which examine the usability aspects of these question lists, an overview of the findings from systematic review articles and literature summaries and lastly by a brief reference to the more general literature identified by the searches and the 'grey' literature.

4 PQPL/QPL Intervention Related Literature

This section provides information concerning PQPL and QPL intervention studies and related literature. Three types of studies are identified. These include those that 1) assess a single QPL/PQPL intervention 2) those that include multiple interventions (e.g. QPL by itself compared with QPL with coaching) and 3) combined interventions where the QPL/PQPL are part of an intervention such as coaching or a pre-visit consultation package. Table 1 and Table 2 (Appendix 1) provide a description and summary of the studies in the first two categories. Although there are a substantial number of studies which discuss 'combined' interventions (Tables 3 and 4) they are problematical in that it is usually not possible to disentangle any effects of the PQPL/QPL from the overall intervention but they may suggest which combined interventions look promising.

Most studies have examined the effect of the PQPL/QPL intervention with regard to outcome variables such as a) total question asking b) content areas of patient question asking c) doctor information giving d) state anxiety e) knowledge recall f) patient satisfaction and g) the total consultation time. These issues are addressed in the summary tables provided (e.g. Tables 1 and 2).

4.1 Single and Multiple QPL Style Interventions

As can be seen from Table 1 and Table 2 (Appendix 1) there were only 24 studies found that related directly to this issue and 20 of these studies, which address the most commonly measured outcome variables, are included in the summary Table 1. Most of these studies were classed by the authors as randomised control trials (RCT) but many studies contained design and implementation issues that affected their strength of evidence rating. Design issues could include a lack of blinding where this was possible (not possible for some interventions such as endorsement), a lack of clarity about methods of randomization or of the study itself, the lack of the use of standardised measures where this may have been appropriate, lack of power analysis, issues concerning statistical analysis or problems identified during implementation which affected the quality of the data collected.

4.1.1 Outcome Variables: Total Question Asking.

As a PQPL or a QPL intervention is designed to increase question asking and thereby increase participation and information received many of the studies assess whether the intervention has increased the total amount of questions asked during the consultation (see summary provided in Table 1 in Appendix 1). This is usually through using an estimate derived from the analysis of the consultation audio-tape (e.g. Bruera et al., 2003; Butow et al., 1994; Clayton et al.; 2007) but sometimes through patient recollection/ self-report (e.g. Bolman et al., 2005; Fleissig et al., 1999). Although audiotape analysis requires standardised rating methods it is thought this method may be less prone to bias than post hoc patient recollections.

As can be seen from Table 1 many of the studies reported no significant differences between the intervention subjects and the controls with regard to total question asking during the consultation (Bolman et al., 2005; Brown et al., 2001; Bruera et al., 2003; Butow et al., 1994; Fleissig et al., 1999; Hamann et al., 2013; Galliher et al., 2010; Kidd et al., 2004; Shirai et al.; 2012; Thompson et al (b), 1990). There is more convincing evidence for an increase in question asking for combined interventions where the QPL/PQPL has been combined with a coaching intervention as can be seen later in Table 3 (see Appendix 1).

Five studies (Brown et al., 1999; Clayton et al., 2007; Middleton et al., 2006; Smets et al., 2012; Thompson et al. (a), 1990) did report significantly more total question asking although the average number of additional questions asked by the patients was variable. For intervention subjects Brown et al. (1999) report an additional 5.5 questions, Clayton et al. (2007) report that intervention subjects asked 2.3 times the number of questions (or about 4 questions), Smets et al. (2012) report an additional 4 questions asked when compared to controls and Thompson et al (a)., (1999) report one additional question. A related study using a patient agenda list Middleton et al. (2006) showed that there was a significant increase of 0.2 patient concerns raised in GP consultations, and if the GP had been trained to use the patient agenda an additional 0.3 concerns were raised (0.5 concerns for both). It can be seen that for these studies the effects are small to moderate.

Clayton et al. (2007) also used a broader outcome measure that combined both total question asking and issues/concerns raised and found a significant difference of 5 points between the means ($p<0.001$) for the experimental and control groups. There was a significant difference of 3 points between the caregivers of intervention and control subjects ($p<0.001$) for a similar variable.

Of interest is that of those 5 studies reporting additional questions or concerns 4 of these studies the QPL or patient agenda list was endorsed by the physician. Of the studies where the doctor endorsed the QPL, only one (Brown et al., 2001) found no effect on total question asking. In the endorsement condition the checked list is requested to be handed to the physician at the commencement of the consultation and thus it would seem more likely to be addressed. This may be an important issue as Bolman et al. (2005) note that some intervention subjects may not use their checklist in the consultation as the doctor did not ask for it. As Clayton et al. (2007) below indicate there can be degrees of endorsement and it is suggested if a QPL/PQPL is used it is not only handed to the doctor but that it is actively addressed by the doctor. Studies by Danesh et al. (2014) and Flocke et al. (2011) indicated that even when a question was identified by the patient, the patient may not ask it and even when they ask the question it may not be answered by the doctor.

Clayton et al. (2007) also examined, through audiotape analysis, the amount of patient question asking of intervention subjects (QPL) in relation to the degree of actual endorsement of question asking behaviour demonstrated by the physicians (none, basic, extended) during the consultation. The total number of patient questions increased with the degree of physician endorsement behaviours ($p<0001$) for QPL subjects. A later study (Clayton et al., 2012) examined this issue for control subjects in the same dataset and found that question asking was not related to physician endorsement behaviours for control subjects. They thus concluded it was the combination of providing the QPL, plus physician endorsement that empowered advanced cancer patients to ask more questions.

Some other general literature may also throw some light on the reason for no differences being found between control and intervention subjects with regard to total question asking. In recent times there has been far more focus not on total question asking itself but on question asking in relation to particular content areas, such as diagnosis and prognosis, and as can be seen from Table 1 many of these studies report significant effects. Perhaps total question asking might be too crude a measure and there is a need to analyses the type and intent of questions asked further. Roter (1977) using a coaching intervention with a QPL raised the issue of differentiating between direct and indirect questions asked of the physician. Roter found that the intervention increased direct question seeking information but not indirect question such as asking for a repetition or explanation of terms used. Cegala et al. (2000) noted that questions also vary by their intent or purpose. The aim of some questions can be to solicit unknown information while other questions may serve to clarify information or to repair communication mishaps in some way. Similarly there are differences between questions by content area such as those that pertain to the medical condition as against those that ask about administrative or social aspects. Davis et al. (2008) have also discussed the patients' reported unwillingness to ask challenging versus factual questions about safety (e.g. have you washed your hands) in consultations.

Three interesting studies reflecting on this issue arise from the general SDM literature. Lam et al. (2013) examined patient question asking in relation to ratings of the doctor's SDM behaviours. They found that question asking was higher in consultations ranked as low in physician SDM behaviours. They noted that some of the question asking involved the patient asking the doctor to explain medical jargon or to repeat what had been said which may reflect question asking in response to poor communication by the physician. This study seems to question the implicit assumption in the QPL literature that increased question asking is an indicator associated with consultation quality and with greater patient participation or shared decision making in the consultation. Tai-Seale et al. (2013) analysed audio tapes of mental health consultations in primary care and found that patients that asked more questions in the consultation rated their physician as having poorer relational communication skills particularly with reference to openness and composure.

Venetis et al. (2014) analysed question asking in relation to patient satisfaction variables and found that the frequency of patient question asking in the consultation was negatively associated with satisfaction with the treatment plan, intentions to adhere to the treatment plan and satisfaction with the surgeon. These findings might suggest that the increase in patient question asking may at least be in part, a response to the perception that the clinician has failed to provide adequate information to the patient during the consultation.

These findings suggest that analyses based on total question asking may be too simplistic and there may be a need to analyse further the intent of patient question asking (e.g. for further information, to clarify an issue, to raise a concern, to request a repetition or to explain medical jargon). For example it could be that intervention subjects are asking more questions requesting information or seeking clarification; but any differences to control subjects may possibly be clouded by control subjects asking more questions for repetitions and/or the explanation of medical jargon. These issues need to be further examined.

Patient characteristics have also been associated with question asking such as younger age, female gender, higher education and middle or higher socio-economic status (Albada et al., 2011; Butow et al., 1994; Davis et al., 2008; Eggly et al., 2006) although these differences are not always found (Clayton et al., 2012; Wells et al., 2004). Eggly et al. (2011) found that question asking was associated with race and that African American patients ask significantly fewer questions in consultations and Volz et al. (2013) also identified racial differences and suggested these needed further investigation. As a result there have been some endeavours to make QPLs more appropriate for those from other ethnic groups but field testing of these initiatives is still in progress (Brown et al., 2013; Eggly et al., 2013). There are also findings that when companions are present question asking by both patients and caregivers are higher (Clayton et al., 2007) although some racial differences have been noted (Street and Gordon, 2008). These authors found that companions with less active participation accompanied black patients and received proportionally less facilitative communication from physicians and suggested that possibly such communicative discrepancies could contribute to racial disparities in cancer care.

The overall literature for studies which involve single and multiple interventions suggests that there is no consistent evidence to suggest that QPL or related interventions are associated with increased question asking by patients during health care consultations. It is suggested that measures of total question asking are refined in future to take account the purpose or intent of the question. There is, however, suggestive evidence that there may be an effect on total question asking when the QPL is actively endorsed by the doctor.

It should also be noted that audiotape analyses of consultations indicate that patient question asking only comprises up to 1-9% of the consultation (Butow et al., 1994; Harrington et al., 2002; Roter, 1977) and as Cegala et al. (2000; 2009) suggests perhaps question asking should not be the only patient communication behaviour examined in these studies particularly given that audio tapes can provide such a rich source of communication data.

4.1.2 Outcome Variables: Question Asking by Content Area

Significant differences for question asking by content area of the consultation have been reported by a number, if not most studies (refer Table 1). The most commonly reported significant findings are for increased question asking about prognosis (Brown et al., 2001; Butow et al., 1994; Clayton et al., 2007) and a non-significant trend was also reported in a study by Brown et al. (1999). Additional questions concerning diagnosis was reported by Bruera et al. (2003), concerning treatment issues by Smets et al. (2012), tests (Brown et al., 1999) recurrence issues (Fleissig et al., 1999) and end of life issues and caregiver issues (Clayton et al., 2007). Where this variable has been examined by studies, Shirai et al. (2012) was the only study to report no differences by content area. Most of the samples above include patients with cancer or advanced cancer.

The size of the effect reported is small. Brown et al. (1999) report a difference in the medians of 1 for tests ($p<0.05$) and a trend for a greater proportion of intervention patients to ask 1 or more questions concerning prognosis ($p<0.09$). Brown et al (2001) report a difference in the medians of 1 for questions concerning prognosis and Butow et al. (1994) report that a greater proportion of interventions subjects than controls (35% vs. 16%) asked 1 or more questions concerning prognosis ($p<0.03$) although there were no median differences in the number of questions asked. However, as Butow et al. (1994) point out that arguably only 1 question is required for prognosis.

For diagnosis questions Bruera et al. (2003) also only report a difference of 1 between the means; Brown et al. (1999) report a difference of 1 between the medians for questions about tests and Smets et al. (2012) regarding treatment issues report a difference between the medians of 3 points when compared to a care as usual control group.

Clayton et al (2007) in a palliative care study also reported on caregiver questions (patients were accompanied). Caregivers and patients in the QPL group asked more total questions than caregivers of controls ($p<0.001$) which specifically included more questions about prognosis and caregiver issues. Patients also asked significantly more questions about caregiver issues.

Only a few of the combined intervention studies (discussed in a later section – see Table 3) examined this outcome variable. Roter et al. (1984) noted increased question asking about diagnosis, prognosis and lifestyle. Van Weert et al. (2011) reported more treatment related questions for subjects given a QPL.

In conclusion with regard to patient (and caregiver) question asking there appear to be a consistent, but small and significant findings with respect to particular content areas of patient question asking – particularly concerning prognosis. Most of the studies above include cancer or advanced cancer patients who may be expected to be more concerned about prognosis issues and thus it is likely the significant content areas may vary by the type of medical consultation/ health condition concerned and the stage of the illness. Further research will be required to investigate this issue.

4.1.3 Outcome Variables: Information Given

Very few of the studies have examined to what extent doctors discussed topics more in their consultations as related to a QPL/PQPL or similar intervention. Hornberger et al. (1997) used a patient concerns checklist with primary care patients immediately prior to their appointment and this was handed to the physician to review during the consultation. Visits using the patient concerns form had approximately 30% more diagnoses discussed per visit ($p<0.05$) and the time spent in discussion of biomedical diagnosis was approximately three minutes longer for the intervention group than for controls ($p<0.05$).

Clayton's et al. (2007) palliative care study reported that from audiotape analysis 23% more issues were discussed during consultations with QPL patients than controls ($p<0.0001$). Seven of nine topics were discussed significantly more often in the QPL group (palliative care service, illness & future expectations, lifestyle and quality of life, support, concerns about professional care, caregiver issues and end of life issues).

Shepherd et al. (2011) used simulated patients to ask 3 questions in general practice consultations and rated physician behaviours (as evidenced from audiotape analysis) in the intervention consultations as achieving significantly higher ($p<0.001$) ACEPP (Assessing Communication about Evidence and Patient Preferences) scores. The ACEPP score was higher by 4.7 points on average which largely reflects an increased communication about presentation of evidence concerning treatment options and a consideration of patient preferences. These differences were achieved without an increase in average consultation time unlike the studies above.

For the combined intervention studies five of six studies that examined this outcome variable reported significant findings indicating that the doctor discussed more issues or gave more information to intervention subjects (Albada et al., 2012a; Brown et al., 2004; Cegala et al., 2000; Finney et al., 1999; Mishel et al., 2009). Van Weert et al. (2011) reported less coverage of some issues e.g. history taking but this was an intended effect of the nurse education intervention.

Given that communication is a complex process, and audiotapes are now routinely used to assess communication elements of these interventions, some further examination of topics doctor's discussed might provide some richer contextual findings concerning the possible benefits of these interventions. However, it should be noted that information given is not the same as information received and recalled. Sandberg et al. (2008) raises the issue of the short-term memory capacity of patients and suggests that the amount of information patient's receive in a consultation is well above these limits which may partially explain the lack of significant findings for knowledge recall discussed below. It would be useful to explore whether the use of a QPL reduces (through structuring) or increases the potential for information overload in consultations.

4.1.4 Outcome Variables: Knowledge Recall

Few of these studies have examined knowledge recall following the consultation. Bolman et al. (2005) used a standardised measure of cardiovascular knowledge at three follow-up points and found that the control group had significantly more knowledge about cardiovascular disease than intervention subjects at two of the three follow-up assessments. The authors cast doubt on their own findings as mean substitution had been used for missing data and the effect disappeared when the analysis only included subjects with complete data at all time points. However, the latter finding could also possibly be affected by statistical power issues. It may have been better to analyse pre-post scores by group. As the intervention was not particularly focussed on cardiovascular knowledge in general it may possibly have been better to focus on recollection of what was actually discussed in the consultation.

Butow et al. (1994) and Brown et al. (2001) tried to address this issue by developing a follow-up rating scale of the patient's recall of issues that were actually raised in the consultation. This strategy, however, raises questions concerning the validation of such measures. Both of these studies found no significant differences between control and intervention subjects for knowledge recall post-consultation. Sander et al. (1996a) also reported no significant findings concerning knowledge recall for a comparison group which were given a health care card/ QPL.

In conclusion there is no evidence to suggest the use of just a QPL/PQPL enhances knowledge recollection but very few studies have examined this issue and for those that have examined it the findings are suspect due to methodological issues. Both Watson et al. (2009) and van der Meulen et al. (2008) noted the varying periods for recall across the intervention studies and Watson et al., (2009) commented on the suitability of some of the instruments used to measure recall.

For the combined intervention studies utilising coaching positive effects on knowledge recall or cancer knowledge are more commonly reported (Albada et al., 2012b; Lewis et al., 1991; Mischel et al., 2009; Sander et al., 1996b). Thompson et al (1990) although finding no differences between groups for knowledge recall did report that the amount of question asking, and the patient asking all the questions they wished to ask, were variables related to increased accuracy of recall ($p<0.05$) although the correlations ($r=0.27$) were fairly small.

4.1.5 Outcome Variables: State Anxiety

Most studies have examined the anxiety of subjects using the Spielberger State Anxiety Inventory (Spielberger et al., 1983) which is a well validated scale. Bolman et al. (2005) found that intervention subjects had significantly less anxiety at 1 month post consultation. Lim et al. (2011) examined anxiety with surgical patients and found a reduction in anxiety between the initial consultation and one day prior to surgery for all patients but there was a trend ($p<0.10$) for the QPL patients to have a greater reduction in anxiety. QPL patients also had significant reduction in anxiety compared to controls at the first out-patient follow-up. Satisfaction with the consultation was also significantly associated with anxiety reduction for all patients although there were no significant differences between the groups for patient satisfaction. Martinali et al. (2001) reported state anxiety was lower for QPL patients post intervention and immediately prior to the consultation. Brown et al. (2001) noted there was no significant difference in anxiety between QPL combined subjects and controls immediately prior to the intervention but noted that QPL subjects in the passive doctor QPL intervention group had significantly higher state anxiety (p=0.04) than both controls and the active Dr QPL group immediately following the consultation. At one week post-consultation there were no differences between the groups. Brown et al. (1999) found no significant differences concerning anxiety between QPL intervention subjects and controls.

For the combined intervention studies Brown et al. (2004) reported that intervention subjects had significantly lower anxiety scores than controls before the consultation (p=0.01) and 2 weeks later (p=0.01) but there were no differences between the groups for anxiety immediately following the intervention. Thompson et al (1999) combined data across his two studies and reported a trend for intervention subjects to have less anxiety following the consultation. Ambler et al. (1999) and Lewis et al. (1991) reported no significant differences for anxiety pre or post the consultation.

Overall the most consistent evidence across all studies is that there are no significant differences concerning anxiety associated with QPL or QPL combined interventions and thus the use of a QPL/PQPL does not appear to involve an unintended negative effective effect concerning an increase in patient anxiety.

4.1.6 Outcome Variables: Patient Satisfaction

Seven single or multiple intervention studies (Butow et al., 1994; Brown et al., 1999; Brown et al., 2001; Clayton et al., 2007; Martinali et al., 2001; Smets et al., 2012; Thompson et al., study 1, 1990) report no significant differences between the intervention and the control groups for patient satisfaction. Three combined intervention studies had similar findings (Ambler et al., 1999; Brown et al., 2004; Tabak, 1998).

Maly et al. (1999) reported significantly higher total scores for intervention subjects using an overall patient satisfaction measure. In the Fleissig et al. (1999) study patient's rated 9 aspects of their satisfaction with care but only 4 aspects appear to be items that would potentially relate to the outcomes of the intervention. For only 1 patient satisfaction item, relating to overall satisfaction, was there a significant difference (p<0.01) between intervention subjects and controls subjects. The authors note however there was no difference in patient satisfaction found between the Health Card (QPL) subjects and a historical control group of patients attending the outpatient clinic prior to the intervention phase. As is found in many of the studies the level of patient satisfaction was high across all patient groups and many patient satisfaction scales and items have been reported to have ceiling effects (Hawthorne, 2006) which may place limitations on these scales to detect differences between groups.

The study by Lim et al. (2011) noted that patient satisfaction appeared to be strongly related to a reduction in anxiety for all patients and there were no differences between groups with regard to patient satisfaction.

Hornberger et al. (1997), using a patient concerns list, noted the experimental group (whose consultations discussed significantly more patient concerns) had a lower level of patient satisfaction than control subjects.

Thompson et al. (1999) had 3 intervention groups. These were A) health concerns list with a 3 question PQPL handed to the doctor; B) encouragement to ask questions with no PQPL or QPL and C) information checklist QPL handed to the doctor. There were no differences between the intervention and control groups regarding patient satisfaction for intervention A) but there were significant differences found for patient satisfaction for interventions B) and C). An analysis which combined data from all intervention groups found there was a trend (p<0.07) for intervention subjects to report higher levels of patient satisfaction.

Middleton et al. (2006) using a patient agenda list which identifies patients concerns found that patient satisfaction was significantly higher for only 1 of 4 patient satisfaction variables and this was satisfaction expressed concerning the depth of the relationship with the doctor. A study by Kidd et al. (2004) which contained 3 intervention conditions (question encouragement; question identification and PQPL; and question identification with PQPL and rehearsal) found no differences between the intervention and controls groups immediately post-consultation but at 3 months follow-up significant differences were found (p<0.05) for all intervention groups compared with controls.

For the combined intervention studies including coaching Lewis et al (1991) reported more patient satisfaction for the child intervention subjects but not for their parents. Tennsted (2000) reported significantly greater satisfaction for intervention subjects. Sepucha et al. (2002) using a consultation planning with PQPL intervention found greater patient satisfaction for the intervention subjects. However, Roter et al. (1977) reported less patient satisfaction for intervention subjects compared with controls (but note there is some confusion concerning the way the data is presented in this study which caused Kinnersley et al., 2007 to later report this, possibly mistakenly, as indicating greater patient satisfaction when it was included in their meta-analysis)

A number of combined intervention studies showed significant effects (4/7 studies) for patient satisfaction but the findings were not all in the same direction. For single and multiple intervention studies only 6/13 studies reported significant effects and again these were not all in the same direction, although for the majority of all studies where a significant finding occurs it is for intervention subjects to report higher levels of patient satisfaction. When some significant effects were shown this was for only a small proportion of the patient satisfaction variables assessed. Given this finding and that overall 10/20 total studies examined showed no effects for patient satisfaction there is insufficient evidence as yet to indicate that that QPL/PQPL or QPL/PQPL combined studies enhance patient satisfaction with the consultation.

Some other studies from the general literature also reflected on the issue of patient satisfaction. McCaffery et al. (2010) noted that although patients with lower levels of education express less desire than more educated patients to participate in health decisions; however, increasing participation, even when it is not explicitly desired, has been associated with greater patient satisfaction (Golin et al., 2002).

Shay et al. (2012) found that patients who asked more unprompted questions during the visit, who expressed physician-prompted concerns during the visit, those who interjected more unprompted assertive responses, and those who reported higher levels of accumulated knowledge were more likely to rate their physician’s relational communication positively. The study particularly noted that an increased number of physician-prompted patient expressions of concern were significantly associated with patient ratings of positive physician relational communication and this is not dissimilar to the notion of doctor endorsement discussed earlier. Cegala et al. (2009) reported that when interacting with high participation patients, physicians engaged in significantly more patient-centred communication overall than when interacting with low participation patients (p=0.01) but particularly with regard to exploring the patient's disease and illness experience. These studies suggest that aspects of physician relational communication may also be related to, and interact with patient participation, and patient satisfaction

A study by Singh et al. (2010) which examined the doctor’s shared decision making behaviour found that patient satisfaction could not be predicted from knowledge of patient involvement preference or clinician SDM behaviours alone but in combination. Other interaction effects between patient reduction in anxiety and patient were also noted in the study of Lim et al. (2010) above.

Patient satisfaction is a complex variable which appears to be subject to a number of interaction effects and thus it may be that it is not so much influenced by only one aspect of interaction, such as question asking, but a range of both doctor and patient communication elements and patient associated factors such as anxiety. Further research in required to investigate these issues. It is also suggested that where patient satisfaction is assessed that validated measures related to the consultation intervention be used (Hawthorne, 2006). Consideration should be given to the use of short, generic, visit/consultation measures rather than disease specific measures to enable comparisons across health conditions and specialities (Hawthorne et al., 2006; Hawthorne et al., 2013)

4.1.7 Outcome Variables: Consultation Length

For the single and multiple QPL intervention studies seven showed there were no significant differences in consultation length when intervention consultations were compared with controls (Butow et al., 1994; Brown et al., 1999; Clayton et al., 2007; Maly et al., 1999; Martinali et al., 2001; Smets et al., 2012; Thompson et al., 1990).

Bolman et al. (2005) reported variable findings with the target visit consultation length being shorter for intervention subjects (2.5 minutes shorter) than controls but a later follow-up consultation was significantly longer (1.6 minutes longer). Brown et al. (2001) reported that although consultations were longer for the QPL interventions combined, consultations were shorter for the QPL with active doctor intervention than for the passive doctor condition (5.86 minutes shorter) and compared with controls (3.59 minutes shorter).

Hornberger et al. (1997) found that consultations for intervention subjects were significantly longer (by 6.8 minutes; 34% longer overall) probably as a result of more patient concerns being discussed. Middleton et al. (2006) using a patient agenda list, with and without GP education, also found consultations were longer by 1-2 minutes on average. It is notable that most studies reporting longer consultation times for the QPL intervention are those that also had positive findings re an increase in questions asked or concerns identified.

For the combined interventions only 5 studies reported consultation length and four of these (Ambler et al., 1999; Brown et al., 2004; Roter et al., 1977; Sepucha et al., 2000) reported no significant difference in consultation time. However, the pre-consultation coaching interventions took between 10 minutes to 1 hour to implement and most studies did not assess this time component which would add considerably to costs. Van Weert et al. (2011) did include the intervention time and found there was a non-significant trend for greater consultation time for the experimental group.

Other broader literature relates to this issue. Eggly et al. (2006) found from the audiotape analysis of consultations that the total number of questions asked was significantly related to the length of the consultation. Tai-Seale et al. (2013) found that if patients brought a list of questions to the consultation that this increased the length of the discussion by 3.2 minutes although the patients rarely did this. Young et al. (2008) found that longer visit duration was associated with more doctor SDM behaviours ($p < 0\ .01$) and these SDM behaviours were influenced by patient-initiated requests for medication.

Although it is hard to be definitive from this data it seems that endorsed interventions, those more likely to obtain an effect, will lead to a small increase in consultation times and therefore cost. If these interventions are to be combined with even a short coaching intervention it is anticipated there would be increased costs both for a potentially small increase in consultation time and an increase in cost associated with the intervention itself.

4.1.8 Other Outcome Variables

A study by Gattellari et al. (2001) using data from Brown et al. (2001) examined patient decision making preferences for the consultation. As part of this study preferred shared decision making style, preferences concerning informational and emotional support and state anxiety scores were obtained from all intervention and control subjects prior to the consultation. This data was examined in relation to the patient perceived achieved SDM role in the consultation and other follow-up measures of state anxiety, knowledge recall and patient satisfaction. There was a match between preferred and perceived SDM for 34% of patients, with 29% more active than desired and 37% less involved than desired and extent of disease was a significant predictor for less involvement than desired. Perceived role (e.g. shared), but not role mismatch, significantly predicted patient satisfaction with the consultation and the perceived amount of informational and emotional support received from the doctor. Patients who reported they had a shared role in the consultation were the most satisfied and those that reported that either they or the doctor had exclusively made the decision were least satisfied. No differences in consultation recall were related to the patient's perceived SDM role. Differences in question asking related to SDM were not reported save for a sub-sample of patients with incurable disease where patient perceptions of involvement in decision making were not associated with the amount of question asking. In the summary table (Table 1) to prevent duplication we did not include this study as a separate entry as the data derives from the Brown et al. (2001) study which is already included.

Some other studies from the general literature reflect on the issues of the preferred and perceived decision making roles in consultations although these studies do not concern the use of a QPL or similar (Brom et al., 2014; El Turabi et al. 2013; McCaffery et al., 2010) and are briefly discussed in Section 4.5.

Smith et al. (2010) concerned the use of a patient decision aid (with and without QPL) to assist decisions concerning bowel cancer treatment for those likely to have lower literacy levels (e.g. it targeted the socially disadvantaged) and it was found to increase knowledge, informed choice and to lessen decisional conflict. However, the participation rate for screening was reduced in the intervention subjects (59%) vs. controls (75%). Of interest was that there were 2 decision making intervention groups and one of these received a QPL as well the decision aid. However, as there were no differences in the results for the 2 decision making intervention arms the data was combined. Thus the addition of the QPL as part of a decision making intervention appeared to provide little additional benefit. The study raises the important issue of addressing literacy levels in the development of QPLs and pDAs but in this study no actual assessment of the literacy of the subjects was undertaken.

4.2 Combined Intervention Studies

Many of the combined intervention studies have been discussed where relevant in the preceding section. Table 4 (Appendix 1) provides the summary details of these studies. It can be seen that many of these studies are coaching interventions which also include a PQPL/QPL within the intervention.

A summary table for the combined intervention studies is provided at Table 3 (Appendix 1). For this table we excluded 10 studies as they either did not assess variables related to question asking even when a PQPL or QPL had been used (Aranda et al., 2012; Davison et al., 1997; Davison et al., 2002; Deen et al., 2011; Shields et al., 2010, Wetzels et al., 2005; Wilkinson et al., 2002) and their primary focus was on other outcome variables. These studies are discussed briefly at the end of this section. Three other studies were currently in progress (Hendren et al., 2010; Masters et al., 2012, Stacey et al., 2012) and have no data to report as yet.

With regard to the issue of endorsement most of these studies are classified as ‘encouraged’ as many of the pre-consultation interventions provide rehearsal and training in question asking with a health professional member of the care team and thus it is felt this does imply some degree of additional encouragement for question asking beyond providing a QPL. A ‘yes’ for endorsement indicates that the PQPL or QPL has been handed to the doctor at the beginning of the consultation or that a facilitator has ensured that the patient’s questions are asked

4.2.1 Combined Interventions: Results Summary

In these intervention studies the PQPL/QPL is included as part of an intervention such as coaching, training in question asking or planning a consultation. As a result it is impossible to differentiate the effect of the PQPL/QPL from the effect of the overall intervention. However, an examination of these findings in comparison with those from the single and multiple intervention studies may indicate whether, for example, coaching with a QPL provides enhanced effects on the major outcome variables discussed. Table 3 (Appendix 1) provides a summary of these studies and their findings.

As can be seen from Table 4 (Appendix 1), eight studies indicated a significant effect for increased question asking or the raising of additional concerns/issues by the intervention subjects. Four studies reported no significant differences between intervention and control subjects. One study (Tabak, 1998) reports no significant difference between the groups but the study has insufficient power and thus it is possible a Type 2 error may have occurred. For the combined interventions studies that examine this variable 66% are finding an effect and this contrasts with 29% of the single and multiple intervention studies. This could be due to a slightly greater degree of endorsement (encouragement) for the combined studies or it may be that the coaching, training and rehearsal concerning question asking has a more direct effect on question asking behaviour.

Four studies examined the type or content of question asking. Roter (1984) reported there were significantly more questions asked by intervention subjects about diagnosis, prognosis and lifestyle issues but the magnitude of the differences were small. Van Weert et al. (2011) reported that intervention subjects asked more questions about treatment.

Roter (1977) found that intervention subjects asked significantly more direct questions than controls and there was a trend for less indirect questions (such as those that are asked of the doctor when the patient does not understand). The ratio of direct to indirect questions was also significantly higher for the intervention subjects. Butow et al. (2004) found that the intervention subjects asked significantly more challenging or direct questions but the magnitude of the difference was small.

All studies that examined the content or type of questions had significant findings, but very few studies examined these aspects. The findings are similar to those for the single and multiple intervention studies.

Concerning the information provided by the consultant for the combined intervention studies five of six studies that examined this outcome variable reported significant findings indicating that the doctor discussed more issues or gave more information to intervention subjects (Albada et al., 2012a; Brown et al, 2004; Cegala et al., 2000; Finney et al., 1999; Mishel et al., 2009). Van Weert et al. (2011) reported less coverage of some issues e.g. history taking but this was an intended effect of the nurse education intervention.

For the combined intervention studies utilising coaching positive effects on knowledge recall of the consultation or knowledge of the health condition are more commonly investigated and reported (Albada et al., 2012b; Lewis et al., 1991; Mischel et al., 2009; Sander et al., 1996b; Van Weert et al., 2011). Five studies found small but significant effects but Mishel et al., 2002 and 2003 found no differences in cancer knowledge post intervention. Sander et al. (1996a) found no effect for knowledge recall for a single intervention comparison group (QPL only) but found significant differences in recall when the QPL was combined with coaching.

Concerning anxiety Brown et al. (2004) reported that intervention subjects had significantly lower anxiety scores than controls before the consultation (p=0.01) and 2 weeks later (p=0.01) but there were no differences between the groups for anxiety immediately following the intervention. Ambler et al. (1999) and Lewis et al. (1991) reported no significant differences for anxiety pre or post the consultation. Roter (1977) reported intervention subjects were rated as demonstrating more anxiety during the consultation. As the findings appear to be somewhat inconsistent there is a need for further research to clarify this issue but it appears unlikely that any unintended adverse effect for anxiety is associated with these interventions.

With regard to patient satisfaction Lewis et al (1991) reported more patient satisfaction for the child intervention subjects but not for their parents. Tennsted (2000) reported significantly greater satisfaction for intervention subjects but Roter (1977) reported less patient satisfaction for intervention subjects compared with controls (but see note on Table 3). Roter (1977) noted that audio tape analysis indicated that more negative affect elements were found in intervention consultations (e.g., anger and anxiety) and consistent with this they reported less patient satisfaction. Sepucha et al. (2002) using a consultation planning with PQPL intervention found greater patient satisfaction for the intervention subjects. A number of the combined intervention studies reported no significant differences concerning patient satisfaction (Ambler et al., 1999; Brown et al., 2004; Tabak, 1998). At this stage in the research there does not appear to be a consistent pattern of research findings with regard to patient satisfaction – the pattern is much as was found for the single and multiple intervention studies.

Only 5 studies reported consultation length and four of these (Ambler et al., 1999; Brown et al., 2004; Roter et al., 1977; Sepucha et al., 2000) reported no significant difference in consultation time. However, the pre-consultation coaching interventions took between 10 minutes to 1 hour to implement and most studies did not assess this time component which would add considerable time and associated costs. Van Weert et al., (2011) did include the intervention time and found there was a trend for greater consultation time for the experimental group. This is an area that requires further research and time measures for both the intervention itself and the following consultation need to be considered as these are quite critical factors for more widespread implementation into routine practice.

Other combined intervention studies have examined different outcome variables and do not focus on, or report, question asking behaviours in the consultation. Aranda et al. (2012) examined whether a combined education and QPL intervention would reduce the distress experienced by chemotherapy patients. There was no reduction in distress for intervention subjects prior to treatment but they experienced less distress before their second treatment when compared with controls. Shields et al. (2010) used a coaching plus QPL intervention to increase the self-efficacy of breast cancer patients to manage and cope with their symptoms. Changes in reported self-efficacy were found to be significant predictors of changes in self – reported anxiety and depression. However, a multiple intervention study by Kidd et al (2004) also focussed on self-efficacy and found that intervention subjects reported greater confidence about asking questions of health professionals but their actual behaviour in the consultation reflected no increase in question asking. Thus whether an increase in self efficacy is associated with an actual change in behaviour needs to be established for studies with this focus.

A study by Wilkinson et al. (2002) used an appointment guidebook intervention which included a space for writing questions but the focus was more centred on appointment keeping. This study did not examine any of the key variables associated with question asking interventions (total question asking, type of question asking, information given, knowledge recall, anxiety, patient satisfaction or total consult time) and therefore was not included in the summary table.

Three other studies used combined coaching interventions with a QPL (Davison et al., 1997; Davison et al., 2002; Deen et al., 2011) but focussed more on shared decision making aspects such as preferred patient role or decision making preferences and patient self-reported participation. Although these studies indicated the interventions could increase patient preferences for a more active role, or enabled them to achieve their preferred decision making role or enhanced their patient participation more broadly; they did not report, or have any discussion of the role of the QPL, with respect to these interventions.

In conclusion the combined studies, such as those that combined a coaching intervention with a QPL appear to produce more consistent findings for an effect concerning increased question asking than did the single and multiple intervention studies. There is however, only one study that compared coaching plus endorsed QPL to an endorsed QPL only intervention (Brown et al., 1999). The authors indicate there was no added value provided by their brief coaching intervention but little detail about the coaching is provided and one of the instructions may have had the perverse effect of discouraging questions (‘You may find the doctors answers your questions without you even asking.’). It does stress however, there is a need for further multiple intervention studies to address such issues.

4.3 Studies that Concern the Use and Acceptability of a PQPL/QPL.

There are quite a large number of studies that examine the development, usability and acceptability of a QPL or PQPL. The Literature Overview for these studies can be found in Table 5 (Appendix 1) and the overall findings are discussed in the following sections. Many of these studies could be said to reflect emerging practice and thus are characterised by a generally low level of evidence. Some studies discuss the development of a QPL, some discuss their use by patients in research settings and more broadly, and many report on their acceptability to patients and patient feedback concerning them.

4.3.1 Patient Usage Rates of PQPLs and QPLs

The use of QPLs by research trial intervention subjects would be expected to be high and most studies report high levels of usage but Bolman et al. (2005) reported that only 73% of the intervention subjects used the QPL in the initial consultation and the use of the QPL declined for later cardiology outpatient visits. Martinali et al. (2001) reported only 75% of her intervention subjects used the QPL in the consultation. For both these studies the QPL was mailed to the patient one week before the consultation. A study by Tennsted (2000) provided intervention subjects with a combined education and QPL intervention three months prior to the index consultation. Over 80% of the intervention subjects failed to bring the QPL to the index visit and this was also true for a study by Wenzels et al. (2005). The implication of these studies would suggest that it may be preferable to give the intervention subjects the QPL material immediately prior to the index consultation. Shepherd and Tattersall (2011) and Dimoska et al., 2008) have suggested sending an information pack to patients before the index consultation to give them more time to consider the QPL but unless this is within two days prior to the consultation (as was the case with Butow et al., 1994) the evidence from this review would suggest this strategy is not advised.

When patients are given the option of using a QPL/PQPL the usage rate reported (40-50%) is only moderate (Albada et al., 2011; Cunningham et al., 2000; Dimoska et al, 2012, Jones et al., 2002; Volz et al., 2013). Albada et al. (2011) using a website pre-visit information application found that only 42% of their sample took up the option to create a PQPL on the website and these tended to be the more highly educated patients. Cunningham et al. (2000) offered parents at a paediatric neurology clinic a PQPL sheet to complete immediately before their consultation and 41% declined the offer and of those that accepted it only 47% used it in the following consultation. Dimoska et al. (2012) reported that 91% of cancer patients offered a QPL asked for it to be sent to them but a follow-up survey indicated that only 44% of the patients had used it in their following consultation. Jones et al. (2002) reported that of patients offered a PQPL sheet to take to their next appointment in three weeks time, only 58% of patients reported that they used it and the doctors reported that only 46% of patients used it in the following consultation. Communication aids were routinely provided to new patients at a breast cancer clinic and 195 patients were prompted to use them. Volz et al. (2013) reported that 81% of these patients reported they wrote a PQPL and 90% of these patients reported using it but only 23% of the patients reported that they showed the doctor the PQPL in the following consultation. The likelihood of making a PQPL increased with the level of the patient’s education but non-white, less educated patients were more likely to show their list to the doctor.

The rates suggested by some of these studies might be influenced by the fact that the PQPL sheet was given to patient some time in advance of the consultation (Jones et al., 2002) although the Cunningham et al. (2000) study reports similar usage rates for those patients given it immediately prior to the consultation. However, the studies suggest that if a PQPL or QPL were to be adopted in routine practice it is quite likely that only 40-50% of patient will use these in the following consultation. Reasons for declining the offer of a PQPL were variable but Cunningham et al. (2000) reported that 29% of parents of patients at a paediatric neurology clinic provided no reason and 24% of parents indicated they had no questions. During the course of this study 31 parents were offered the question sheet for a second time and 55% of these parents did not wish to use it again.

4.3.2 Perceived Acceptability and Helpfulness of a PQPL/QPL

Although the usage rates are not as high as one might expect, for those that use a QPL or PQPL the feedback is generally favourable. Brown et al. (2011) report that the feedback from all 20 subjects used to pilot test the 33 item QPL-Clinical Trials was favourable although clinicians had more mixed feelings as some felt that its use may overburden patients with too much information to consider. The same study indicated that although the majority of these patients preferred a paternalistic decision making style they felt that the QPL-CT could be useful before, after and during the consultation.

Clayton et al. (2003) report that most patients (22/23) had positive feedback concerning a QPL with 112 questions for palliative care patients. Despite its length 80% of patients reported they felt it was the right length and 80% felt that the 20 minutes prior to the consultation was sufficient time to read it and to identify questions that they wished to ask. Some patients (25%) reported they found it overwhelming to read the brochure and 40% of patients indicated that some questions made them feel nervous although pilot-study data indicated there was a significant decrease in state anxiety after seeing the QPL brochure and seeing the doctor. Thirty-five percent of patients felt it would have been better to have received the QPL brochure 2-3 days before the consultation. Most health professionals and doctors also provided positive feedback and the pilot study indicated that end of life issues should be included in the QPL despite some initial reservations expressed by health professionals. Unfortunately the study does not provide details about which questions from the QPL were actually asked by patients during the pilot–study consultation and given the length of this QPL the analysis might suggest ways to potentially shorten the QPL. Clayton et al. (2007) reported that consultations using the QPL palliative care took an additional 7 minutes of consultation time which they acknowledged could potentially be reduced if the QPL were shortened.

Cunningham et al. (2007) reported that although only 47% of patients used the PQPL, 88% of these users liked the PQPL sheet. Fleissig et al. (1999) reported that 50% of intervention patients found a QPL enhanced the consultation and a similar result was reported by Fleisher et al. (2008) using a web-based aid although the sample was very small. Glynne-Jones et al. (2006) using a survey of patients given a QPL found that 65% found the QPL helpful and that 1/3 of patients reported asking more questions due to receiving a QPL. Herbert et al. (2009) reported that 75% of caregivers found a QPL for caregivers made it easier for them to ask questions.

Martinali et al. (2001) found that 38% of cardiology outpatients given a cardiology QPL found it useful and 38% did not but 71% of those that used it thought they would use it again. The QPL covered all aspects of cardiology treatment and thus some components (e.g. diagnostic issues, risk factors) may be less useful to patients receiving outpatient care.

Shirai et al. (2012) compared the ratings of advanced cancer patient concerning the usefulness of pre-consultation materials between QPL intervention subjects (QPL plus hospital information sheet) and controls (hospital information sheet only). QPL intervention subjects 1) rated the QPL material as more useful for asking questions (p=0.033) 2) more useful for understanding the treatment plan (p=0.051) and 3) they were more willing to use these QPL materials in the future (p=0.006) than controls. These findings occurred despite there being no differences concerning the total questions asked, or questions by content area, between the groups.

4.3.3 Studies that Concern the Development of a QPL

There are relatively few studies that discuss in any detail how a particular QPL has been developed. Most have used focus groups or semi-structured interviews of patients and providers to identify themes or questions for inclusion and some iterate this process until no new topics/themes/ questions can be identified. Bender et al. (2008), for example, identified 200 questions concerning cancer pain from semi-structured interviews; so while a large number of questions might be identified from focus groups QPL designers need to be more mindful that not all these questions need be included. The questions are usually reviewed and then categorised into clusters/themes under various topic headings. Examples of this process are provided by Clayton et al. (2003), Herbert et al. (2009) and McJannett et al. (2003) but it should be noted that the thematic analysis is not always well described and neither are the methods to select the final items.

Many of the QPLs that have been derived from such processes are quite long but generally range from about 17 questions to 112 questions although one author reported a QPL that was 33 pages long (Langbecker et al., 2013). It is evident from the studies contained in the literature overview table is that there has been little consideration of the length of QPLs and whether this factor may potentially impinge upon their use not only in research settings but more particularly in routine care. No studies were found that examined issues concerning the most appropriate length for a QPL and Dimoska et al. (2012) have identified this as an issue that requires investigation. Dimoska et al. (2008) noted that the 112 item palliative care QPL (Clayton et al., 2007) did not produce an increase in the average number of questions asked compared to other studies and thus suggested it could be shortened. As Miller (1956) indicated humans are beset with limits to short term memory (7 units +/- 2) and even if the checklist is ticked by the patient, if many questions are ticked, the patient may have difficulty in remembering or prioritising the ones they most wanted to ask during the course of the consultation. Sandberg et al. (2008) analysed the number of units of information that doctors provided in anaesthesia consultations and noted it far exceeded patient’s short-term memory capacity and thus memory factors might influence such outcomes as knowledge recall. Brown et al. (2011) also noted that clinician’s feedback on a QPL for information about clinical trials was to raise concerns about whether it may overburden patients with too much information to consider.

Once the QPL has been designed it is usually pilot tested with a small number of target patients but often it is only general feedback that is solicited (e.g. did you understand the questions in the QPL, was the QPL useful, etc). It may also be critically reviewed by clinicians and other health professionals and then it is usually refined before being used in the field.

However, it may not be sufficient to ask pilot subjects whether they understood the QPL overall but it may be necessary to undertake a linguistic validation approach which asks patients to explain what each question means to them in their own words. This is a useful strategy to identify problematic wording in questions but is one that does not appear to have been utilised or considered at the pilot stage. As a QPL is like a survey without response categories, appropriate methods for survey/scale construction and development should be used (Streiner and Norman, 2003; Warwick and Lenninger, 1975).

A study by Brown et al. (2012) provides an example of a more thorough pilot testing approach for a QPL for clinical trials (QPL-CT). During the pilot testing phase of the 33 question QPL-CT the authors identified what questions patients actually asked, the questions they wanted to ask but did or did not ask, and the reasons for this. This data indicated there were only 17 questions that 60% of the pilot subjects actually asked and this analysis of endorsement patterns might indicate, for example, that the QPL could be shortened. An examination of the questions the patient's wanted to ask but did not ask (e.g. re costs, conflict of interest) might also suggest that other strategies to address some of these issues might be required. Some of these questions might be better addressed through an information leaflet or through leaving space for individual questions at the end of the QPL.

4.3.4 Adaptation for Particular Population Groups

Some studies have referred to the linguistic adaption of measures for use in another country (Caminiti et al., 2010; Goss et al., 2013) and in these instances it is necessary that appropriate and recognised methods for translation are used. Alden et al. (2014) suggests the need for cultural tailoring to improve the effectiveness of patient decision aids in culturally diverse groups and the theoretical framework suggested would be equally relevant to the development of communication and information aids for people from culturally diverse groups.

Eggly et al. (2013) discuss the customisation of a QPL for African American patients in an endeavour to reduce known racial disparities associated with cancer chemotherapy treatment but this is yet to be pilot-tested. Cross cultural and linguistic validation for such studies is essential. As Walczak et al. (2013) noted concerning the development of an end of life issues QPL there was a need to develop different but equivalent version of their QPL to accommodate differences between the Australian and US approaches to end of life discussions

Posma et al. (2009) in a study concerning older patient's information needs prior to chemotherapy noted older people may benefit from aids to enhance question asking and the recall of information which may suggest the need for a short and well structured QPL for these patients. Eggly et al. (2006) also found that older patients asked significantly less questions.

Although most studies concerning the development of A QPL have indicated they have assessed the readability level of their QPL, Ashton et al. (2010), Mc Caffery et al. (2010) and Katz (2007) suggest the need to adapt communication aids to better address the needs of low literacy subjects. Katz (2007) noted there were no differences in total question asking for low literacy patients but they asked significantly less questions concerning key medical aspects of their care. Low literacy subjects also asked the doctor to repeat information more often. Mc Caffery et al. (2010) noted that QPLs may have a role in empowering patients with lower literacy to feel able to ask questions in consultations.

4.3.5 Conclusions re Question List Acceptability and Usability Issues

Generally patients that actually used a PQPL/QPL list provided found them useful and acceptable (usually over 75%). Martinali et al. (2001) reported lower rates for perceived usefulness but despite this 71% patients indicated they would use the QPL again. This study raises the issue that the QPL provided may need to be directly related to the consultation type – for outpatients a QPL that addresses issues across all treatment phases may not be so relevant or useful. Similarly an overall QPL concerning phases of cancer treatment may not be as relevant to patients about to undergo chemotherapy as a QPL which directly concerns the chemotherapy treatment.

Studies concerning usage rates for QPL/PQPL noted that when there is a choice about using the list that the patient usage rate (40-50%) is much less than occurs in research studies (usually over 70%). This is an important finding as it would suggest that in routine practice only half the patients would make use of one.

In experimental trials intervention subjects are strongly encouraged to make use of the QPL/PQPL provided but even so two studies (Martinali et al., 2001; Bolman et al., 2005 indicated only 70-75% of the intervention subjects used the list during the intervention and the study by Tennsted (2000) indicated that only 20% of patients brought their list to the consultation. A factor related to this is the time before the list/sheet is presented in relation to the intervention; if the time period before the intervention is long patients may forget to bring and use their QPL/PQPL in the index consultation. Thus it is suggested that when PQPL and QPL lists are used it should be immediately prior to the intervention as occurred for most of the studies reviewed.

Concerning the development of QPLs it is suggested that pilot studies should examine the endorsement rates (how often the question is actually asked by patients) for all questions as occurred in the study by Brown et al. (2012). For QPLs that are currently being used in the field it is suggested that endorsement rates are checked as this might suggest some ways to shorten some very long QPLs, such as the palliative care QPL developed by Clayton et al. (2003). As Dimoska et al. (2012) indicate further research will need to address the issue of the most appropriate length of a QPL. On the other hand some QPLs only include 3 questions (Galliher et al., 2010; King et al., 2013; Shepherd et al., 2011) and could potentially be too short but there is very limited evidence concerning short QPLs and the two studies that have examined their use have conflicting findings.

A related issue is whether it is better to use a patient generated list of questions (PQPL) or a prepared QPL which lists suggested questions to ask and the patient then usually selects a number of questions which they wish to discuss. Wells et al. (2004) suggested that that the limitations of QPL are that listing questions for patients to tick is patronising and paternalistic and it might even influence their agendas. Cunningham et al. (2000) reported that doctor feedback indicated that PQPL lists were useful in identifying unexpected questions they would have not thought to address and for identifying issues that the patient did not understand. On the other hand, Albada et al. (2011) noted that the PQPL was used mainly by higher educated subjects and that some subjects reported difficulty in writing questions. As a result they concluded that it may have been better to use a QPL. Jones et al. (2002) found that patients from lower socio-economic classes are less likely to write a list of questions. However no research was identified which actually compared these question list interventions. Many QPLs in current use also provide a space at the bottom for patients to add any questions of their own.

Another research gap that has been identified is the need to identify culturally sensitive QPLs for non-English speaking patients (Dimoska et al., 2008) and to tailor QPLs for those from culturally diverse backgrounds (Alden et al., 2014; Eggly et al., 2013; Walczak et al, 2013). Similarly there is a need to tailor question lists for patients with low literacy levels (Ashton et al., 2010; Katz, 2007; McCaffery, 2010).

4.4 Systematic Literature Reviews and Literature Summaries Concerning Question Lists

Fourteen articles were identified that have summarised the literature concerning the effectiveness of question lists as communication/information aids or aids to enhance patient participation. Many of these summaries have a broader focus than just QPL/PQPL style studies (e.g. Kinnersley et al., 2007) and include intervention studies concerning other communication/information aids (e.g. brochures, leaflets, multi-media, videotapes)some of which do not contain a QPL or PQPL. Where meta-analytic analyses have been undertaken QPL style interventions are usually included under 'written interventions' and the data analysis has not examined the use of a QPL/PQPL intervention separately. The literature overviews for these papers are found in Table 6 (Appendix 1).

The early review articles (Gaston et al., 2005; Harrington et al., 2002; Parker et al., 2005; Ryan et al., Tattersall et al., 2003) are based on very limited literature as at this time relatively little QPL research had been undertaken. Readers are referred to the article summaries provided.

Two of the reviews (Kinnersley et al., 2007; Spiegle et al., 2013) have included meta-analyses. The Kinnersley et al. (2007) review is a very comprehensive Cochrane Collaboration review which has a particularly excellent coverage of early RCT studies in this field. However, in this review the QPL interventions are subsumed within a broader category of 'written interventions' for the purpose of analysis and thus this category includes studies where no PQPL/QPL has been used. Many of the QPL interventions included were combined interventions (e.g. coaching and QPL). Kinnersley et al. (2007) (for written interventions) noted a small but significant increase in total question asking and patient satisfaction for the studies overall. However, for those written interventions using a QPL it is evident from the tables provided that there is probably no significant effect for patient satisfaction. A small increase in consultation time across all studies was noted although it was not significant.

Spiegle et al. (2013) concerns patient decision aids and other decision support interventions for cancer treatment and the 3 QPL studies included (Butow et al., 1999, 2004; Clayton et al., 2007) are included in the category of 'other decision support interventions'. They noted a small but significant difference in total question asking for the three QPL studies and there were no significant differences found for patient satisfaction and anxiety. They noted that across the studies included in the 'other decision support interventions' there was a significant improvement for patient knowledge, but there was only 1 QPL study included for this analysis as most were studies using audio tapes as an intervention to aid recall.

Rodin et al. (2009) examined evidence concerning doctor-patient communication with cancer patients. The review examines only three QPL studies (Brown et al., 2004; Butow et al., 2004; Clayton et al., 2007). A QPL was found to increase the number of total questions asked by patients (2 trials) or questions specifically related to the prognosis (1 trial). QPL use was associated with no increase (1 trial) or a decrease (1 trial) in patient state anxiety. One trial with a combined intervention including a QPL found the intervention group was significantly more anxious than the control group at pre-consultation (p=0.04). The data examined concerning the use of a QPL was limited.

The review by Dimoska et al (2008) was specific to QPL intervention for cancer and examined 15 studies. The review reports that the use of a QPL did not increase total question asking but that some studies showed significant effects concerning a small increase in questions concerning prognosis. Generally no adverse effects, such as anxiety, were reported. It is recommended that when QPLs are used they are endorsed and addressed by the doctor. The issue of the length of QPLs is raised as an important research issue and this review notes a lack of studies investigating the use of QPLs with non-English speaking patients. The article by Friedrichsen (2008) also raises the issue of the optimum length for a QPL and raises cultural issues with respect to the use of QPL interventions.

Henselmanns et al. (2013) examined patient-based interventions to increase participation in oncology consultations. Five QPL interventions were identified across 12 papers. The review found there was no evidence to support that QPLs increased total question asking but identified that some studies had found a significant effect relating to the content area of question asking (prognosis). The review reports there were no significant effects for patient satisfaction or consultation length. Effects of the QPL interventions could only be observed for intermediate outcomes (consultation behaviour) rather than longer term outcomes including physical and psychological well being or other factors such as patient satisfaction and consultation duration.

The reviews of Van Meulen et al. (2008) and Watson et al. (2009) concerned the recall of knowledge or medical advice. Van Meulen et al. only noted the QPL study by Brown et al. (2001) which indicated a doctor endorsed QPL enhanced recollection of the consultation. Watson et al. cited 2 studies, the one above and one by Butow et al (1994) and noted these studies had conflicting findings.

4.5 Other General Literature

Some additional studies provided some information that was considered relevant to this general discussion but did not involve a PQPL/QPL intervention directly. Some of these papers focused on patient characteristics associated with question asking behaviour during consultations (e.g. gender, ethnic/race differences, age, level of education, literacy level) or addressed areas of patient information needs and these have been referred to where relevant in the text.

Some papers examined the degree of patient activation in relation to how this increased the patient-focus of the doctor's SDM behaviour during the consultation (Cegala et al., 2009; Young et al., 2008). Lam et al. (2013) noted the presence of more doctor SDM behaviours was associated with greater patient satisfaction.

Tiedjie et al. (2013) noted that the use of decision aids did not promote shared decision making behaviour of patients or doctors in the consultations but were used as flexible artefacts which embodied patient's and clinician's existing roles in decision making and this may potentially apply to the use of communication/information aids.

Quite a number of these papers focussed on aspects of shared decision making and the perception of patient preferences for decision making and whether these preferences were achieved during the consultation (for example, Brom et al., 2014; El Turabi et al., 2014). Brom et al. (2014) reviewed 44 studies pertaining to this aspect and found that most patients preferred a shared decision making role in consultations (26 studies). The mean congruence between preferred and perceived decision making role was 60%. Where no congruence occurred most patients preferred more involvement (33 samples) but for 9 patient samples patients preferred less involvement. Studies indicated that younger patients preferred a shared or more active role as did more highly educated patients. The review suggested that adopting a similar approach to all patients (e.g. encouraging participation) is not likely to meet patients' needs since preferences for participation vary amongst patients.

El Turabi et al. (2013) undertook a national cancer patient survey which asked patients whether they were as involved in decisions about their treatment as they would have liked. They found 72% of patients were satisfied with their degree of involvement although there were substantial differences found across cancer treatment areas. Younger patients, very old patients and ethnic minorities reported less positive responses. McCaffery et al. (2010) also reported that patients with lower levels of education express less desire than more educated patients to participate in health decisions; however, increasing participation, even when it is not explicitly desired, has been associated with greater satisfaction with the consultation (Golin et al., 2002)

Tak et al. (2013) also examined patient preferences for decision making in relation to the costs of care. Although most patients preferred to leave decision making to their doctor (71%) those that preferred to participate in decision making had a small but significant increase in length of stay and associated costs of treatment.

Some QPL studies, for example Gattellari et al. (2001) and Butow et al. (1994) have also examined decision making preferences. Butow et al. (1994) found that question asking was greater for both control and intervention subjects who had an active decision making preference. Gattellari et al. (2001) noted that patients who reported playing a shared role in the consultation were the most satisfied and those that reported that either they or the doctor had exclusively made the decision were least satisfied. As is indicated by these studies audiotapes of consultations have the potential to provide far richer data about communication behaviours than has often been explored by QPL/PQPL research studies.

Similarly, some papers have been included in the 'general' list as they raise research issues concerning the use of patient decision aids which may also be useful to consider in QPL research. Charles et al. (2005) notes the choice of aids should be relevant to the context and goal of the treatment at the time of consultation and that this should also drive the selection of appropriate outcome measures.

Some studies have investigated the use of web sites/ internet to provide patients with pre-consultation training sometimes in association with the use of a PQPL or QPL (e.g. Albada et al. 2012a, b). Coleman et al. (2005) found that following the introduction of a Frequently Asked Questions module that internet posts concerning treatment aspects declined but posts about prognosis and end of life issues increased which is similar to some findings concerning the use of a QPL increasing questions about prognosis. Heyn et al (2013) used an interactive patient assessment tool with cancer patients concerning symptoms prior to the consultation and found patients asked significantly more questions about symptoms and were more active participants in the consultation. Davison et al. (2003) used a computer intervention (Patient Information Program) to assess patient's information needs and then tailor the information provided to those needs.

Dear et al. (2011) reports on patient assessments of the acceptability (89%) of a website concerning cancer trials which included a QPL and Oermann et al. (2001) examined patient's usefulness ratings for ten major patient resources placed on the internet. Of these the *Be Informed: Questions to ask your Dr before Surgery* was rated as the most valuable resource and the authors recommend that this plus *Prescription Medicines and You* should be made available to all patients.

Although not suitable for all patients, or all intervention types, the use of the internet to provide pre-consultation information, including question lists, could be investigated further. In the following section some available 'grey' literature concerning the use of a PQPL/QPL has also been described.

Some studies have been included in the overview of the general literature as they describe other communication aid interventions which have been included in some of the analyses of the systematic reviews. The literature overview relating to other general literature is provided in Table 9 in Appendix 1.

5 The 'Grey' Literature Concerning Patient Question Lists

This section examines the practice and associated literature in relation the use of QPLs/PQPLs. The search strategy found a number of reports, book chapters, presentations and question prompt lists currently in use in the health care setting. The practice literature will be divided into two sections looking at general documents retrieved in relation to the use of QPLs/PQPLs (see Table 7, Appendix 1) and a section looking specifically at QPLs/PQPLs identified by our search (see Table 8, Appendix 1).

5.1 Practice Literature

Practice literature was identified from Australia, the UK, the USA and an internationally authored report. These documents included several reports, book chapters, PowerPoint presentations, a clinical trial registration and one conference abstract.

The majority of the material identified had a main focus on shared decision making or other related topics with the inclusion of some discussion on the use of QPLs/PQPLs. There were fewer documents that had a major or primary focus on QPL/PQPLs.

A book chapter by Shepherd and Tattersall (2011) contained a section on the benefits of using QPLs/PQPLs in preparing cancer patients for the consultation. A brief overview of the evidence is provided relating to the benefits of a QPL in helping patients to ask questions about difficult subjects such as prognosis. They argued that there was evidence that endorsement of the QPL by the physician increased questions and that the use of a QPL did not increase consultation length. Concerning the latter point, although this is generally true, this review did find evidence that most studies that reported the intervention increased question asking also found a short increase in consultation time (e.g. 2 -7 minutes).

In particular, the authors point to recent work done in Australia that produced five recommendations for the implementation of QPLs (Dimoska et al, 2008). These recommendations can be summarised as follows:

- Providing training and education for health providers and other staff about the evidence for QPLs and providing reminders to health and administrative staff on the benefits of QPLs to help foster a culture of support for patients to use QPLs/PQPLs;
- Allowing staff at each site to develop the implementation process and procedures to suit their individual needs;
- Enlisting the support of QPL champions from all levels to encourage clinic wide acceptance;
- Patients should receive a QPL when they first attend a clinic as part of an information pack mailed to them prior to the consultation to allow time to properly consider their questions. This should also be supplemented by QPLs handed out by staff;
- Educating patients about the QPL and encourage them to ask for, take and use the QPL.

The points raised by Dimoska et al. (2008) are useful and generally supported by the findings of this report. However, the suggestion to send an information pack to patients before the index consultation to give them more time to consider the QPL is not supported by the evidence in this report unless this is within two days prior to the consultation (as was the case with Butow et al., 1994). As suggested this would also need to be supplemented by a QPL to be handed out by staff immediately prior to the consultation in case patients forget to bring the QPL with them for the consultation.

Shepherd and Tattersall (2011) already noted that providing a QPL can help cancer patients ask difficult questions, such as questions about prognosis. In a recent text on prognosis, a chapter by Gramling et al. (2012) discusses issues related to prognosis in advanced illness. They suggested introducing a question prompt list as a way to help support patients and families. A QPL can help patients and families contemplate what they wish to know, identify whether they are ready, express how they would like to discuss prognosis and be involved in decisions, determine when they would like information, and state how much information they want to receive and in what form they would like that information. An example of a QPL that focuses specifically on prognosis was provided. The QPL includes four questions concerning what the patient can expect in the future, if their life span will be shortened, what are their possible time frames and best and worst-case scenarios. The QPL is presented as an example only and no evidence is provided as to the use and/or endorsement of the QPL by patients or family members.

These authors make a very important point regarding the use of QPLs; that they can be a useful communication tool, however, they are not essential in patient-centred care, nor are they a substitute for effective human interaction in the conversation.

In a presentation on the use of QPLs and coaching, Butow (2013) outlines the evidence for QPLs and coaching patients in getting the information they need by asking questions. Butow argues that there is evidence that coaching patients in asking questions does not significantly increase consultation length and is associated with small increases in patient satisfaction (quoting Kinnersley at. al., 2007[1]). However this is only the case if the intervention is provided just before the consultation. Butow also states that the ‘3 questions’ concept introduced by Shepherd et al. (2011) is effective in both encouraging patients to be more involved in decision making and encouraging doctors to provide more information. It is important to note, however, in regards to Butow’s findings about patient satisfaction, that this is based on the Kinnersley et al., review, (2007), where a number of the interventions included were combined QPL intervention studies or other written interventions and so the results cannot be attributed to QPLs alone. Similarly, this review reports no consistent findings for patient satisfaction and it is noted that the evidence for the ‘3 Questions’ concept is limited to a study using simulated patients (Shepherd et al., 2011).

Butow raises several questions about QPLs and coaching that current research has not been able to answer. These include:

- How long should a QPL be?
- When should a QPL be given?
- Should A QPL be general or specific?
- Should a QPL be tailored or patient derived?
- Is coaching necessary?
- What would make coaching more effective?

These questions are important ones and are also raised by this report.

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[1] Butow (2013) refers to Kinnersley (2007) review using the copyright date of 2009. However the publication citation is 2007.

Further questions could be raised from a review of evidence relating to patient communication (Epstein and Street, 2007). The QPL and PQPL methods are mentioned in the report as important communication approaches that can be used in combination with a range of strategies to improve communication. This report found that in relation to end of life stages and treatment discontinuation decisions, QPLs were well received but their impact was not clear.

Three reports were identified in relation to the MAGIC program evaluation in the UK, some of which have been reported elsewhere in this report. King et al. (2013) reports the main evaluation report of the MAGIC program. The MAGIC program is mostly concerned with the implementation of initiatives to promote shared decision making between patients and physicians. One specific strategy is the ‘Ask 3 Questions’ initiative also based on the ‘3 questions’ concept introduced by Shepherd et al (2011). As stated earlier in this report, further field testing of this concept is needed. In particular the MAGIC report (King et al., 2013) provided little quantitative data for the ‘Ask 3 Questions’ initiative.

Another report by the Office of Public Management (2013) provided a qualitative review of the implementation of the MAGIC shared decision making initiatives by seven primary care or hospital-based teams. This report was a ‘learning’ report that documented the experiences of these teams in implementing their chosen SDM initiatives, including four teams who implemented the ‘Ask 3 Questions’ materials. The teams implemented the material at varying levels from simply providing the materials to patients to adapting the material to their specific needs, explaining the material to patients and encouraging patients to use the material. There were several points raised in relation to the implementation and use of the ‘Ask 3 Questions’ material and these included

- Decision and communication aids should be short and simple and preferably kept to one page.
- Information provided to patients was not enough to encourage questions. A poster campaign was not felt to be effective. Patients often didn't understand shared decision making and so it needed to be explained to patients. Patients also needed encouragement (e.g. be given permission) to ask questions.
- Written information was not helpful for those with learning disabilities and low levels of literacy. A film to be shown in the waiting room was developed in an attempt to overcome this problem, although it wasn’t certain how effective this was.
- There was anecdotal evidence that the 'Ask 3 Questions' material could lead to more collaborative and informed decision-making. For example, one patient noted that ‘while in the past they had been happy to take the doctor’s advice they had also felt dissatisfied with the treatment options and would have liked to ask if there were other ways they could have done things’.

An earlier report related to the MAGIC program (Fischer and Ereaut, 2012) looked at doctor patient communication. This report was the result of a comprehensive interview and consultation process that included experts, health professionals and patients. This report provided detailed background information about patient and doctor communication, in particular the context and issues relating to question asking. One of their main findings was that fear/anxiety is what often drives the doctor-patient communication dynamic. This report helped shape the MAGIC Program.

The MAGIC program has been promoted within the UK as a way to improve shared decision making and includes the use of a brief QPL 'Ask 3 Questions' as evidenced by the presentation to health care staff by Thomson (no date) in which the program is explained to staff, what it's benefits are and how to get involved. This presentation on the MAGIC program highlighted the broader context of QPLs in SDM. Also a key point is that SDM is much more than just tools, it is about a 'consumer focussed' approach to consulting (aided by communication or decision support).

A large body of work relating to the development of QPLs has occurred in Australia, which has been widely reported in the academic literature (e.g. Clayton et al., 2005). Few evaluations at the practice level were identified in the literature. A number of QPLs have been developed for cancer patients by Sydney University and the NSW Cancer Institute. Few evaluations were identified in the practice literature concerning how these tools have been used. This may not necessarily indicate that evaluations were not done but that they were reported through other means, such as academic publications (refer to Table 5).

A summary of key achievements in relation to patient education and support by the Cancer Institute NSW (2011) included the development of four QPLs for cancer patients, including questions to ask your surgeon, questions to ask your oncologist, questions to ask your haematologist and questions to ask about complementary therapies. These QPLs are reviewed in the following section. Work on QPLs is currently continuing in Australia with a study by a University of Sydney team (Ahmed et al., 2014) on the development of a question prompt list for parents and carers of children diagnosed with attention-deficit/hyperactivity disorder.

An Australian review of evidence produced by the Health Issues Centre (Bruce et al., 2008) looked at shared decision-making as a way to improve community participation. As part of this review it was found that question prompt lists were an effective way to engage consumers in shared decision-making at the individual level and when implemented appropriately. A policy document produced by the Health Issues Centre (2007) indicates that QPLs have been used to support shared decision making but notes that there was strong evidence for the use of decision aids and communication aids in relation to shared decision making. The policy report also summarises consultation findings and notes that "At an individual level, consumers spoke about wanting more information, more control over their care and treatment and greater involvement of their carers". The planning section of the report recommends using decision aids and question prompt lists where possible at the individual patient/carer level and at the Unit/Department level as a potential method to improve consumer and carer participation.

There has been work undertaken in the USA on the implementation of patient QPLs, including that done by the Agency for Healthcare Research and Quality (AHRQ). There were few documents in the practice literature found in relation to this work. A PowerPoint presentation by Seubert (2008) outlines the 'Questions are the answer' initiative and introduces the web-based question builder developed by the AHRQ. This presentation raised some important points regarding the use of QPLs, such as the limitations of both web based and hardcopy QPLs for use with patients with low levels of health and general literacy. The Health Literacy course developed by Marshfield Clinic, (Seubert, 2008) in collaboration with other health organisations used a number of different strategies to improve the skills and knowledge of low literacy patients.

Further work in relation to online QPLs is underway, as evidenced by the clinical trial registration for the study "Developing an Online Clinical Trial Specific Question Prompt List" (Brown, 2014).

One final important document was identified that concerned the use and implementation of guidance and coaching in relation to patient deliberation and communication. The use of guiding and coaching aims to help patients make higher quality decisions (Stacey et al., 2012). This document provides an update of standards as defined by the International Patient Decision Aids Standards (IPDAS) Collaboration for decision coaches to follow. The IPDAS standards document states that guidance should be provided within a patient decision aid if a list of questions and/or an invitation for users to identify questions to ask the practitioner (or decision coach) is provided. Enhancing patient skills in communication includes helping patients prepare questions and identify concerns or providing a list of questions for the practitioner.

5.2 Question Prompt Lists on the Internet

Our search identified a total of 31 QPLs available on the internet and one in the academic literature. The majority of these, 17, are from the USA. The remaining 14 are from Australia as is indicated in Table 8 (Appendix 1).

The predominant clinical contexts for the use of QPLs in both Australia and USA are cancer care and palliative care settings. The American Cancer Society has developed seven separate QPLs for the following types of cancer: breast cancer, colon and rectum cancer, lung cancer, melanoma, skin cancer (Basal and Squamous Cell), prostate cancer, and a general cancer QPL. These were all updated in 2013. All of these QPLs are quite long, being either 10 or 11 pages and containing 47 to 56 questions. Many of the questions are the same for all of the different types of cancer.

Although comprehensive in nature, and divided into sections such as: diagnosis, treatment plan and treatment, so patients would not refer to all questions at the one time, these longer QPLs could be overwhelming. A reasonable level of both general literacy and health literacy is required to understand some of the terms used in the QPL, such as 'clinical trials', 'pathology', and 'imaging scans'. This limits the usability of the QPL to educated patients with a good level of health literacy.

The American Society of Clinical Oncology (2011) developed a general oncology QPL which has three pages and 57 questions divided into the following sections: General Information (8Q); Symptoms (5Q); Diagnosis (8Q); Staging (4Q); Treatment (14Q); Clinical trials (9Q); Support (7Q); Follow-up care (2Q). Although it is a long QPL, there are some good, simple explanations provided for 'medical terms' to help patients with a low level of health literacy to understand the suggested questions.

In contrast to the very long QPLs developed by the American Cancer Society and American Society of Clinical Oncology, a very short QPL developed by the Agency for Healthcare Research and Quality (AHRQ) (2010) was found '*Get more involved with your Health Care: Do you know the right questions to ask?* This is a simple, user-friendly, 10 questions QPL that has a general health focus that can be used in a range of health settings, including primary care. This QPL is written in both Spanish and English languages.

The National Heart, Lung and Blood Institute, part of the USA Department of Health and Human Services, has developed a QPL for people with high blood pressure. This 14 question QPL is simple and easy to use. The inclusion of a question re 'goal' of medical treatment / management is a good way to help the patient focus the discussion with the doctor around a specific goal for medical treatment. Questions regarding lifestyle factors such as diet and exercise are also included as this is relevant to the management of high blood pressure.

The American Heart Association (2013) developed a two page document that can be printed from their website. The document contains useful web links to specific QPLs, so is best accessed on the website. This summary document includes the main points for patients to consider when preparing for a visit to the doctor including hints for how to improve communication. It is a little bit hard to navigate to find exactly the QPL the patient may want. However, there is some good general information regarding improving communication with your doctor, seeking a second opinion and how to find another doctor. Due to web based nature of the document it cannot be accessed by people who are not computer literate or who do not have easy access to the internet and thus has a limited audience.

Another web based QPL is a ‘QPL builder’ that has been developed by the Agency for Healthcare Research and Quality, part of the USA Department of Health and Human Services. This online interactive document enables people to create a specific QPL for each medical visit. It is a helpful tool for someone who is both computer literate, with internet access, and who has a basic level of health literacy.

The other ‘sub-set’ of QPLs from the USA are those that have been developed or adapted by health care providers such as: The Cleveland Clinic, Health New England, John Hopkins Medicine centres, and the University of California San Francisco Medical Centre. These QPLs are tailored for patients who want to use the specific services of the health care providers and ‘fit’ the organisational context. They are therefore ‘organisational specific’ rather than ‘disease specific’. Notable features of these QPLs are as follows: the John Hopkins Medicine centre’s QPL is different from other QPLs as the focus is not purely on helping patients to seek information from their doctor about the medical condition and treatment, but also encouraging them to ask about the impact of the treatment on work / life / home as well as reflection by the patient regarding how they feel about the doctor's communication style.

Health New England’s QPL is a simple, relatively easy to use QPL for general discussions with doctors. Space is provided for patients to write notes next to each question when they are in the consultation with their doctor and this enables the one document to contain both the questions and answers for easy future reference by patients.

The USA National Family Caregivers Association has a different audience for their QPL, in that it has been developed for the carer on behalf of the care recipient and not the ‘patient’ themselves as is the case with nearly all the other QPLs. This is a two page QPL with 48 questions for family carers who need information regarding health care for their care recipient. The suggested questions cover not only medical information but also the impact of the care recipient's illness on the carer.

Another QPL for family caregivers was developed in the USA as part of a pilot study by Herbert et al (2009). This study conducted pilot testing of a Question Prompt Sheet to encourage family caregivers of cancer patients and physicians to discuss end-of-life issues. The researchers developed a question prompt list with the help of family caregivers (current caregivers and bereaved caregivers) and health care professionals with at least 2 years' experience in end-of-life care. A QPL of 25 questions was developed with two headings: 'Common questions asked' and 'When my loved one isn't getting better'. Space for patients to tick the questions they wanted to ask was provided next to the questions as well as space to write down any extra questions. This QPL was then tested with 56 caregivers. The QPL was given to caregivers in the waiting room and they were encouraged to fill it out and give it to the physician in the consultation. The question most ticked related to the side effects of their loved one's medications.

As earlier stated in this review, Walczak et al. (2013) noted concerning the development of an end of life issues QPL there was a need to develop different but equivalent version of their QPL to accommodate differences between the Australian and US approaches to end of life discussions.

Thirteen of the fourteen Australian QPLs identified in our search are exclusively focussed around cancer care and palliative care. The other QPL is from Asthma Australia and one concerning ADHD (attention deficit hyperactivity disorder) is under development. Of the thirteen QPLs for cancer and palliative care, seven have been developed by the University of Sydney and two are collaboration between the University of Sydney and Australian Cancer Trials. One QPL developed by Cancer Australia, was based on work undertaken by the University of Sydney.

The Northern Territory Department of Health also adapted work done by the University of Sydney to provide some questions for cancer patients to ask. The Queensland University of Technology have also developed one QPL and one has been developed by the Peter MacCallum Cancer Centre in Victoria. The pamphlets developed by the University of Sydney encourage a 'key message' about question asking by all having the quote that '*asking questions is important*'. They all, however, assume a certain level of literacy and health literacy, for example, some patients may not know what a 'multidisciplinary team' is and may not be concerned with this. The QPL from the Queensland University of Technology also uses a key message 'It's okay to ask'.

Clayton and Butow (2006) from the Medical Psychology Research Unit, University of Sydney developed a QPL booklet for palliative care patients who have been referred to a palliative care team. This QPL has a total of 112 questions, and although general patient feedback indicated this was acceptable, patient endorsement rates were not examined. The questions are divided up into sections with descriptive headings and lines for extra questions to ask. Although a very long QPL, most people were happy with the length of the QPL (Clayton, 2003). The QPL starts with questions regarding the 'palliative care team'. From a patient perspective this may not be the most important set of questions to have at the beginning and may serve as a deterrent for patients to go through this section to get to sections such as symptoms, treatment and medications that the patient may relate to more readily. It is suggested it may make more sense to have the questions regarding the palliative care team near the end. Another comment regarding this QPL is that some of the information the questions are trying to elicit could be provided to the patient by way of an information brochure on the palliative care team, leaving the focus of the questions on the health and medical questions that may be more relevant for patients. An examination of patient endorsement rates could clarify this issue.

The main ‘set’ of QPLs developed by the University of Sydney (2008) is focussed around the cancer patient’s discussions with medical specialists such as oncologists, surgeons and haematologists. These pamphlet style QPLs are shorter in length being all around 50 questions. Tick boxes are a ‘user friendly’ feature for patients. Questions appear on one page so that the QPL doesn't appear too burdensome. Questions are tailored for the audience and are designed to be given to the patient prior to, but on the same day, as the specialist appointment. There are, however, a number of double barrelled questions that may be complex for lower level literacy patients to understand and may be difficult for the doctor to provide both a simple and comprehensive answer. Generally, double-barrelled questions should be avoided in the development of QPLs. There is no indication on the website of how relevant these questions are to patients or how frequently they are asked by patients. The questions appear not to have evolved very much over the various updates.

Large print versions of some of these QPLs are available on the website which improves the ‘usability’ of the QPLs for patients who may have some minor vision impairment. According to a report by the Cancer Institute, these resources have also been translated into 20 different languages (Cancer Institute, 2011).

In 2009, The Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) at University of Sydney, developed a QPL on complementary therapies. This QPL was targeted at cancer patients who may be seeing a range of health professionals, not just medical specialists. It follows a similar format to the other QPLs by CeMPED but the questions are quite different and tailored to the range of complementary therapies available. The headings allow patients to concentrate on the sections they are interested in, such as: ‘questions to ask your health professional about specific therapies (Mind body techniques, Body-based practices), Biological-based therapies (Nutrition, Herbal medicine), and other therapies (Flower remedies and homeopathy)’. It is not, however, entirely clear which of these questions should be asked of which health professional.

In 2010, University of Sydney, in collaboration with Australian Cancer Trials, developed two QPLs for patients regarding cancer clinical trials. The first of these is a 20 question QPL for those patients who are considering joining a clinical trial and the second, a 34 question QPL, for those patients who have decided to join a cancer trial and wish to ask questions regarding that specific trial. These QPLs are building on the foundational cancer related QPLs developed by Sydney University.

The Northern Territory Department of Health (2014) has a short QPL on their ‘Cancer Journey’ webpage that includes 11 questions for patients to ask their doctor regarding their diagnosis of cancer and treatment options. This is an example of a short QPL provided on a website that appears to have been adapted from the work done by Sydney University. At the end of the QPL, information is provided for patients regarding the QPL developed by Sydney University for the Cancer Institute of NSW if they want more questions to ask their health care professionals.

Also adapted from work undertaken on cancer QPLs by University of Sydney, is a QPL contained in a report on the emotional and social impact of cancer by Cancer Australia (2013). This QPL covers a range of general questions regarding cancer diagnosis and treatment.

The QPL developed by the Peter MacCallum Cancer Centre in Victoria (2009) is a QPL for cancer patients who are about to undergo chemotherapy treatment. There are 27 questions appearing under the following headings: 1) How is chemotherapy given; 2) What does chemotherapy feel like; 3) Ways of reducing your risk of infection; 4) Managing fatigue; 5) Reducing nausea and vomiting, managing constipation and diarrhoea; and 6) Taking care of your mouth. There are between 3 and 6 questions under each heading. There are tick boxes that allow patients to tick questions relevant to them. This QPL is to be used in conjunction with a DVD "*Looking after yourself during chemotherapy*". Patients are encouraged to bring both the QPL with questions ticked and the DVD to the education session. Space on the back of the page is provided for patients to write more questions. Although an innovative combination of the QPL and DVD, the audience is limited to those patients who have access to a DVD player.

The School of Public Health, Queensland University of Technology (2008), developed a QPL '*It's okay to ask*'. This QPL is specific to patients with brain tumours, their families and health care professionals. This 181 question QPL has been divided up into two sections, with the first section being a list of 31 general questions. If patients wish to ask further questions, they are directed, by specific page references, to the relevant sub-set of questions in the additional 150 questions at the back of the QPL. The design of this QPL helps the patient navigate through a large number of questions to find the most relevant ones for them at the time. In addition, at the beginning of the document, there is a section that aims to coach patients regarding question asking. Patients are also provided with regular sections for them to write their own questions. The format of this QPL is thought to be 'user-friendly' for patients; however the QPL does contain a number of double barrelled questions which increases the complexity of the document for some patients and, in total, it appears too long.

Asthma Australia has developed a ten question QPL for asthma patients to review before going to a medical appointment. It is a succinct QPL targeted at asthma patients. There are web-links for some question so if patients want more information about the topic they can go to that page and get more information to help them better understand the issue, for example, exercise, medication and asthma management plans. This is a simple; user friendly QPL for asthma patients, however as it is web based it is not accessible to those who are not computer literate or who do not have internet access.

5.3 Conclusions re the 'Grey' Literature

QPLs are currently most prevalent in the USA and in cancer and palliative care clinical settings in Australia. The majority of the practice literature identified in the grey literature search had a primary focus on shared decision making or other related topics with the inclusion of some discussion of the use of QPLs/PQPLs. There were fewer documents that had a larger or primary focus on QPL/PQPLs. Key points from the grey literature regarding the use of QPLs are that QPLs are important communication tools that can influence the development of an effective relationship between patients and health professionals, in the broader context of shared decision making and patient centred healthcare. QPLs in isolation, however, are not a substitute for effective communication and do not enhance or 'fix' poor communication between doctors and patients. The development of clinician communication skills needs to be further addressed through clinical training and other peer led strategies.

QPLs need to be adapted to the local or organisational context and may be more ‘user friendly’ when contained as a shorter, more specifically focussed set of questions.

There appears to be a growing trend for QPLs to be interactive and web-based. This is effective for those patients who are computer literate and have access to the internet, however will exclude patients with low levels of health, general literacy and computer literacy from accessing the information.

This review of the 31 QPLs available on the internet, highlighted some common themes and factors in relation to the usability of the QPLs. Many QPLs, in an attempt to be comprehensive in nature, are extremely lengthy and could potentially be overwhelming for some patients. As indicated earlier in this report it is suggested that an analysis of patient endorsement patterns (e.g. an examination of the questions patients actually ask) might suggest some effective strategies to shorten QPLs. It is considered that shorter, one page QPLs may be more user friendly for patients but research concerning the optimum length of a QPL is required. Language of the QPL is also an important factor for consideration. Many QPLs contain ‘medical terminology’ that is not widely understood by patients with poor health literacy. Complex questions (including double barrelled questions) are also not easy for people with a general low level of literacy to use or for doctors to answer and should be reworded. QPLs that had space for patients to write answers to the questions and those that provided some explanation of medical terms may be more ‘user friendly’ for many patients.

Some of the QPLs contained general ‘tips’ for improving communication with doctors. This is seen as a useful addition to the QPL as it provides some ‘context’ for the QPL as a tool to be used as part of the conversation between the patients and doctor or health professional.

The majority of QPLs covered medical and treatment related issues. Some QPLs covered topics such as the impact of the illness and treatment on the patient’s life. One QPL that was developed for use by family carers covered a broader scope of ‘life impact’ aspects of the disease for both patient and the caregiver.

QPLs have a place in clinical care as a tool to assist the clinician to more effectively engage their patient in their care. The grey literature indicated that improved communication between doctors and patients may have some influence over improving immediate outcomes. QPLs, however, cannot be seen as a ‘quick fix’ to chronic and perhaps cultural and systemic problems in communication between health professionals and consumers and their introduction should be accompanied by strategies to improve both patient and clinical awareness of this approach (King et al., 2013).

6 Conclusion

This review has examined the evidence concerning the use of Question Prompt Lists and Patient Question Lists as communication aids to enhance patient question asking and patient participation in health and medical consultations. A comprehensive research strategy (see Section 3) detected a large number of articles concerning PQPL and QPL studies including intervention/experimental studies as well as those that concern acceptability and usability evaluations.

6.1 Findings from Intervention Studies

Single and multiple interventions studies provide the clearest evidence available. These studies usually assess a single QPL/PQPL intervention in relation to a control group or placebo control group. Multiple intervention studies might examine two intervention arms such as QPL with a coaching intervention, and a QPL alone, and both of these interventions compared to a control condition. Combined intervention studies have usually included both some form of coaching as well as the use of a QPL/PQPL but this means it is hard to differentiate the effects of the QPL/PQPL from the coaching/educational component of the intervention.

Many of the studies reported no significant differences between the intervention subjects and the controls with regard to total question asking during the consultation (Bolman et al, 2005; Brown et al, 2001; Bruera et al, 2003; Butow et al, 1994; Fleissig et al, 1999; Hamann et al, 2013; Galliher et al., 2010; Kidd et al, 2004; Shirai et al; 2012; Thompson et al. (b), 1990).

Five studies (Brown et al, 1999; Clayton et al, 2007; Middleton et al, 2006; Smets et al, 2012; Thompson et al (a), 1990) did report significantly more total question asking although the average number of additional questions asked by the patients was variable. For two of these studies there was only up to one additional question asked although for three studies the increase in question asking was more substantial. For intervention subjects Brown et al., (1999) report an additional 5.5 questions, Clayton et al., (2007) report that intervention subjects asked 2.3 times the number of questions (or about 4 questions) and Smets et al. (2012) reported a similar figure.

Of note is that of those 5 studies reporting additional questions or concerns in 4 of these studies the QPL or patient agenda list was endorsed by the physician. Of the studies where the doctor endorsed the QPL, only one (Brown et al., 2001) found no effect on total question asking. In the endorsement condition the checked list is handed to the physician at the commencement of the consultation and thus it would seem more likely to be addressed. This may be an important issue as Bolman et al. (2005) note that some intervention subjects may not use their checklist in the consultation if the doctor did not ask for it. As Clayton et al (2007) indicate there can be degrees of endorsement and thus it is suggested if a QPL/PQPL is used it is not only handed to the doctor but that it is actively addressed by the doctor.

For combined interventions eight studies indicated a significant effect for increased question asking or the raising of additional concerns/issues by the intervention subjects. Four studies reported no significant differences between intervention and control subjects. One study (Tabak, 1998) reports no significant difference between the groups but the study had a small sample and it is suspected it had insufficient power to detect a difference. For the combined interventions studies that examine this total question asking 66% found an effect and this contrasts with 29% for the single and multiple intervention studies (including those with no endorsement). This could be due to a slightly greater degree of endorsement (encouragement) for the combined studies or it may be that the coaching, training and rehearsal concerning question asking has a more direct effect on question asking behaviour. A multiple intervention study by Brown et al. (1999) examined the use of a QPL with and without coaching and reported no additional effect of coaching which may suggest that the degree of endorsement of a PQPL/QPL is the critical issue. However, one study is insufficient evidence and further research needs to examine this issue more comprehensively.

Although the research is not definitive the results suggest that an actively endorsed QPL is likely to have more effect on total patient questing asking. Some authors have suggested (Cegala et al., 2000; Roter et al., 1997) that ‘direct’ questions which seek additional information need to be differentiated from ‘indirect’ questions (e.g. in response to the doctor) that concern a request for repetition or the explanation of medical jargon. There is some suggestive evidence (Lam et al., 2013; Tai Seale et al., 2013 and Venetis et al., 2014) that crude counts of total questions asked may cloud potential differences in the type of question asking between intervention and control subjects.

The evidence is more promising with regard to PQPL/QPL effects on the content of questions asked. Significant differences for question asking by content area of the consultation have been reported by a number, if not most single and multiple intervention studies (refer Table 1). The most commonly reported significant findings are for increased question asking about prognosis (Brown et al., 2001; Butow et al., 1994; Clayton et al., 2007). Additional questions concerning diagnosis was reported by Bruera et al. (2003), concerning treatment issues by Smets et al. (2012), tests (Brown et al., 1999) recurrence issues (Fleissig et al., 1999) and end of life issues and caregiver issues (Clayton et al, 2007). Where this variable has been examined by studies Shirai et al. (2012) was the only study to report no differences by content area.

Only a few of the combined intervention studies examined the content of questions asked. Roter et al. (1984) noted increased question asking about diagnosis, prognosis and lifestyle. Van Weert et al (2011) reported more treatment related questions for subjects given a QPL. However, for all the studies it should be noted that the effects are small – it may be that only 1 more question is asked or that the proportion of patients asking 1 or more question in the topic area is significantly greater.

In conclusion with regard to patient (and caregiver) question asking there appear to be consistent, but small and significant findings with respect to specific content areas of patient question asking – particularly concerning prognosis. Most of the studies above include cancer or advanced cancer patients who may be expected to be more concerned about prognosis issues and thus it is likely the significant content areas may vary by the type of medical consultation/ health condition concerned and the stage of treatment. Further research will be required to investigate this issue.

Very few of the single or multiple intervention studies examined to what extent doctors discussed topics more in their consultations as related to a QPL/PQPL or similar intervention (Hornberger et al., 1997; Clayton et al., 2007; Shepherd et al., 2011) but these studies have found significant effects. For the combined intervention studies five of six studies that examined the topics discussed reported significant findings indicating that the doctor discussed more issues or gave more information to intervention subjects (Albada et al., 2012a; Brown et al, 2004; Cegala et al., 2000; Finney et al., 1999; Mishel et al., 2009).

Given that communication is a complex process, and audiotapes are now routinely used to assess communication elements of these interventions, some further examination of topics actually discussed/information given might provide some richer contextual findings concerning the possible benefits of these interventions.

There is no evidence to suggest the use of just a QPL/PQPL enhances knowledge recollection but very few studies have examined this issue and for those that have examined it the findings are suspect due to methodological issues concerning the assessment of recall or knowledge. For the combined intervention studies utilising coaching, positive effects on knowledge recall or cancer knowledge are more commonly reported (Albada et al., 2012b; Lewis et al., 1991; Mischel et al.; 2009; Sander et al., 1996b). Thompson et al (1990) although finding no differences between groups for knowledge recall did report that the amount of question asking, and the subject asking all the questions they wished to ask, were variables related to a significantly increased accuracy of recall ($p<0.05$) although the magnitude of the correlations ($r=0.27$) were fairly small.

It is thought that the lack of consistent and significant findings concerning knowledge recall might potentially also be influenced by limits pertaining to short-term memory capacity (Sandberg et al., 2008). Watson et al. (2009) also raised issues concerning memory factors as well as the suitability of the assessment instruments that were used to measure recall. Both Watson et al. (2009) and van der Meulen et al. (2008) also noted the varying periods for recall across the intervention studies.

Although there are some conflicting findings (see summary Tables 1 and 2) the most consistent evidence across all intervention studies is that there are no significant differences concerning anxiety associated with QPL or PQPL interventions and thus the use of a QPL/PQPL does not appear to involve an unintended negative effective effect concerning an increase in patient anxiety.

Seven single or multiple intervention studies (Butow et al., 1994; Brown et al., 1999; Brown et al., 2001; Clayton et al., 2007; Martinali et al., 2001; Smets et al., 2012; Thompson et al., Study 1, 1990) report no significant differences between the intervention and control groups for patient satisfaction. Three combined intervention studies had similar findings (Ambler et al., 1999; Brown et al., 2004; Tabak, 1998).

A greater proportion of combined intervention studies showed significant effects (4/7 studies) for patient satisfaction but the findings were inconsistent as one study indicated less patient satisfaction for the intervention subjects (Roter et al., 1977). For single and multiple intervention studies only 6 of 13 studies reported significant effects and again not all reported an increase in patient satisfaction (e.g. Hornberger et al., 1997), although for the majority of all studies where a significant finding occurs it is for intervention subjects to report higher levels of patient satisfaction. When some significant effects were shown this was for only a small proportion of the patient satisfaction variables assessed. Given this finding and that overall 10/20 total studies examined showed no effects for patient satisfaction there is insufficient evidence as yet to indicate that that QPL or QPL combined interventions enhance patient satisfaction with the consultation. This contrasts with the findings of the Kinnersley et al. (2007), often referred to in the 'grey' literature, where a small but significant effect for patient satisfaction was identified but it is noted this analysis included both single and combined QPL style interventions as well as other written interventions and of course does not include the more recent research studies.

Overall there were no consistent findings concerning an effect on knowledge recall, anxiety and patient satisfaction but these are complex variables with known interaction effects (e.g. anxiety reduction has been associated with an increase in patient satisfaction across all patients; broader aspects of physician relational communication may interact with patient satisfaction). Further research is required to investigate these interaction effects and to also identify more sensitive and valid measurement tools for these variables (patient satisfaction measures are prone to ceiling effects).

For the single and multiple QPL intervention studies six showed there were no significant differences in consultation length when intervention consultations were compared with controls (Butow et al., 1994; Brown et al., 1999; Clayton et al., 2007; Martinali et al., 2001; Smets et al., 2012; Thompson et al., 1990). Three studies (Brown et al., 2001; Hornberger et al., 1997; Middleton et al., 2006) reported longer consultations for QPL style interventions overall and it is notable that most studies reporting longer consultation times for the QPL intervention are those that also had positive findings re an increase in questions asked or concerns identified. Despite finding a significantly longer consultation time for the QPL intervention subjects overall Brown et al. (2001) reported that consultations were shorter for the QPL with active doctor intervention (proactively addresses patient questions) than for the passive doctor (passively responds to patient questions) condition (5.86 minutes shorter) and compared with controls (3.59 minutes shorter).

For the combined interventions only 5 studies reported consultation length and four of these (Ambler et al., 1999; Brown et al., 2004; Roter et al., 1977; Sepucha et al., 2000) reported no significant difference in consultation time. However, the pre-consultation coaching interventions took between 10 minutes to 1 hour to implement and most studies did not assess this time component which would add considerably to costs. Van Weert et al., (2011) did include the intervention time and found there was a non significant trend for greater consultation time for the experimental group.

Although it is hard to be definitive from this data it seems that endorsed interventions, those more likely to obtain an effect, may lead to a small increase in consultation times and therefore cost. If these interventions are to be combined with even a short coaching intervention it is anticipated there would be increased costs both for a potentially small increase in consultation time and an increase in the cost associated with the intervention itself. The intervention time for single intervention studies is likely to be quite short, but is rarely stated, and cost estimates for routine implementation would need to take this factor into account.

6.2 Findings from Acceptability and Usability Studies

The use of QPLs by research trial intervention subjects would be expected to be high and most studies report high levels of usage, however, four studies (Bolman et al., 2005; Martinali et al., 2001; Tennsted, 2000; Wenzels et al., 2005) reported lower rates of QPL/ PQPL usage by the intervention patients. In all these studies the PQPL/QPL was mailed out to the intervention patients some time before the consultation. The implication from these studies would suggest that it may be preferable to give the patients the QPL material immediately prior to the consultation or immediately adjacent to it (2 days or less).

Studies concerning usage rates for QPL/PQPL noted that when there is a choice about using the question list that the patient usage rate (40-50%) is much less than occurs in research studies (usually over 75%). This is an important finding, when considering more widespread implementation of QPLs, as it would suggest that in routine practice only half the patients would make use of one.

Feedback from patients also suggests that the QPL concerned needs to be directly related to the type of consultation (Charles et al, 2005) for example outpatient care or chemotherapy (Martinali et al., 2001; Langbecker et al., 2012) and not be a QPL that covers all phases of treatment or care. It is also suggested that the QPL is given at the initial consultation for that phase of care rather than midway during a course of treatment.

Some research issues were identified such as investigating the optimum length of a QPL, given that so many QPLs are quite lengthy (over 50 questions to 112 questions). In the development and pilot testing phase for a QPL it is suggested that patient endorsement rates are examined (e.g. how many of these questions were actually asked by patients in the pilot consultations) and this should provide a number of potential strategies to shorten these tools. Is there any need to include questions that are rarely asked by patients (e.g. re costs, conflict of interest issues) or are their other ways these particular information needs could be addressed? Designing a QPL is similar to designing a survey or questionnaire without response categories and it is suggested that established methods for survey and questionnaire design are utilised where appropriate (Streiner and Norman, 2003; Warwick and Lenninger, 1975).

The majority of studies have examined the use of a QPL/PQPL in medical specialties (particularly cancer) and fewer studies have examined the use of PQPL and QPL strategies in general practice settings. Some studies (Cegala et al., 2000; Hornberger et al., 1977; Roter 1977, Roter 1982; Middleton et al., 2006) have reported some positive findings with respect to the effectiveness of the QPL/PQPL in increasing question asking or issues identification in these settings. Other studies such as Tennsted et al. (2000) and Wetzels et al. (2005) experienced problems of low usage of the QPL/topic list by elderly subjects who were sent the materials some time prior to the index visit. Concerning the use of a QPL/PQPL in general practice, given the diversity of the consultations concerned, it may be difficult to design a QPL that is relevant to the majority of patients. Most of these studies used a PQPL. A more recent approach is to suggests three generic questions for patients to ask (Galliher et al., 2010; Shepherd et al., 2011; King et al., 2013), but there is little evidence available as yet concerning the effectiveness of this approach and caution is advised concerning its adoption until the evidence is more substantial.

Findings from the ‘grey’ literature indicate that within Australia there appears to be more routine use of QPLs in cancer settings and a number of QPL resources are provided by the Cancer Institute of NSW. However, many web sites present QPLs as tools for use by patients or doctors without any supporting evidence concerning their development and use. QPLs are currently most prevalent in the USA and in cancer and palliative care clinical settings in Australia.

Key points from the 'grey' literature regarding the use of QPLs are that QPLs are important communication aids that can influence the development of an effective relationship between patients and health professionals, in the broader context of shared decision making and patient centred healthcare. QPLs in isolation, however, are not a substitute for effective communication and cannot 'fix' poor communication between doctors and patients. The development of effective communication skills and the appropriate use of communication aids needs to be addressed through clinical training and other peer led strategies. Patient understanding and awareness of the approach also needs to be facilitated as part of any implementation in routine care.

QPLs have a place in clinical care as a tool to assist the clinician to more effectively engage their patient in their care. QPLs, however, cannot be seen as a 'quick fix' to chronic and perhaps cultural and systemic problems in communication between health professionals and consumers.

6.3 Concluding Remarks

Overall the literature suggests that research on the effectiveness of QPL and PQPL interventions is still at a relatively early stage, with only suggestive rather than clear and definitive findings, and this review has also identified a range of research gaps that need to be addressed. Some of these include the need for further studies to address the issue of whether a QPL associated with a short coaching/educational intervention is more effective than a QPL alone. A study comparing PQPL and QPL approaches could also be useful given feedback on the pros and cons associated with these lists (Wells et al., 2004; Albada et al. 2012a; Jones et al., 2002) Further research also needs to investigate the optimum length of a QPL as many of the QPLs used are lengthy instruments containing a number of questions that most patients are unlikely to ask. On the other hand there is extremely limited evidence concerning the use of very short QPLs for general practice settings, such as those used in the 'Ask Three Questions' initiative in the UK, and given this, caution is advised concerning the adoption of such strategies until the evidence is more substantial.

In conclusion there is suggestive evidence that an appropriately designed and relevant QPL/PQPL, that is actively endorsed by the physician, and provided immediately before the index consultation, may increase patient question asking in consultations, and may lead to more information being provided by the doctor in these consultations. .

Our recommendation is that the QPL should also be given immediately prior to the index consultation as studies where the material has been sent to patients a week or more before the consultation report low usage rates as patients forget to bring the materials to the consultation (Bolman et al., 2005; Martinali et al., 2001; Tennsted, 2000; Wenzels et al., 2005). Shepherd and Tattersall (2011) and Dimoska et al. (2008) suggested sending an information pack to patients before the index consultation to give them more time to consider the QPL but unless this is within two days prior to the consultation (as was the case with Butow et al., 1994) the evidence from this review would suggest this strategy is not advised. Patient feedback from the usability literature and the study by Dimoska et al (2012) also suggest it is best to provide the QPL to new patients when first diagnosed or at the beginning of a particular phase of treatment (e.g. radiotherapy, chemotherapy) rather than those who are midway through a phase of treatment.

It should be noted that the effect of these interventions on consultation length is still unclear as the findings are not consistent but the evidence suggests that when patient question asking and participation is increased then there may be an associated small increase in consultation time (Clayton et al., 2007; Eggly et al., 2006; Hornberger et al., 1997; Middleton et al., 2006).

The acceptability evidence strongly supports the notion that when QPL/PQPLs are used they perceived as useful by patients in both framing questions and enhancing the consultation (see Section 4.3.2.).

Given the above there is sufficient evidence to support some further trials and use in routine practice, particularly in medical specialty areas where an appropriately designed and tested QPL/PQPL may be available. Only one study, Dimoska et al. (2012), concerning the broader implementation of QPLs in routine care, was identified (cancer patients seeing medical and radiation oncologists) although Belkora et al. (2008) and Pass et al. (2012) also noted some barriers to implementation (resource constraints, conflicting priorities, doctor forgetfulness to request the list). Further implementation research is required across other settings. If so, careful consideration should be given to the findings of Dimoska et al. (2012) which identified a range of factors which can facilitate implementation. These included the promotion by clinical champions, negotiation with the clinics concerning dissemination methods, and strategies to raise both patient and physician awareness.

In considering such initiatives consideration should also be given to the fact that the evidence from this review suggests that only up to 50% of patients' may make use of a QPL/ PQPL if offered one and given thus some analysis of the cost effectiveness, and return on investment, of such initiatives could be considered. Other cost factors to be considered also include the development and testing of a QPL/PQPL if one is not available. Cost estimates for routine implementation would need to take the time for the implementation of a PQPL/QPL into account and any effect such as an estimated small increase in consultation time. As well there would be costs involved in suggested strategies to enhance clinician and patient awareness of the approach and costs for clinical training. There is little cost data available as yet as most studies have only focussed on consultation time and have not considered implementation and development costs and thus more information on the costs associated with routine implementation are required.

The is a need for further research to develop culturally sensitive QPLs for non-English speaking patients (Caminiti et al., 2010; Dimoska et al., 2008; Goss et al., 2013) and to tailor QPLs for those from culturally diverse backgrounds (Alden et al., 2014; Eggly et al., 2013; Walczak et al, 2013). Similarly there is a need to tailor question lists for patients with low literacy levels (Ashton et al., 2010; Katz, 2007; McCaffery, 2010).

There is a need for further longitudinal research concerning the repeated use of QPLs. There is only limited research available in the literature concerning this aspect but the suggestion is that patients find it less useful over time for repeated consultations concerning the same phase of treatment (Bolman et al., 2005; Cunningham et al., Martinali et al., 2001). Dimoska et al. (2012) suggest that patient information needs may change during the course of the illness and different QPLs may need to address different treatment phases.

Some studies have investigated the use of computer-generated individualised question lists, usually in combination with an education package. The Agency for Healthcare Research and Quality in the US has provided a website where a patient can build their own QPL for their next consultation. Brown et al. (2014) are testing the QPL-CT, for questions about clinical trials, in an online format. Although not all patients will have access to the internet or be as adept at using it, these strategies also warrant further investigation.

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Appendix 1: Literature Overviews and Summaries

Table 1 Summary of Findings: Single and Multiple PQPL/QPL Interventions

First author	Intervention type	Endorsed Y/N	Total QA	Content QA	Dr Information given	Knowledge Recall	Anxiety	Patient Satisfaction	Consult Time	Strength
Single QPL interventions										
Bolman, et al. 2005	QPL	N	(NS -patient rated)			** less	* less		shorter for initial consult, longer post consult	acceptable
Bruera, et al. 2003	QPL	N	NS	* diagnosis					NS	promising
Butow, et al. 1994	QPL	N	NS	* prognosis				NS		acceptable
Clayton, et al. 2007	QPL	Y	** more	** prognosis, caregivers, lifestyle				NS	** longer	supported
Fleissig, et al. 1999	Health Care Card/QPL	N	No differences re recollection of number & type of questions asked save for *recurrence					* only for overall visit satisfaction; 1/9 variables		emerging/ low
Galliher, et al. 2010	3Q	prompted	NS							acceptable
Hamann, et al. 2013	QPL	N	NS	NS						emerging/ low
Lim,et al. 2011	QPL						* Reduction pre-consult to follow -up	Related to anxiety level only		acceptable
Maly, et al. 1999	QPL choose 2 Q	Y						* greater	NS	emerging
Martinali, et al. 2001	QPL	N					* less	NS	NS	acceptable
Shepherd, et al. 2011	3Q	N			** more information ACEPP				NS	acceptable
Shirai, et al. 2012	QPL	N	NS	NS						promising
Smets, et al. 2012	QPL	Y	** more	** treatment				NS	NS	acceptable
Related Single interventions										

First author	Intervention type	Endorsed Y/N	Total QA	Content QA	Dr Information given	Knowledge Recall	Anxiety	Patient Satisfaction	Consult Time	Strength
Hornberger, et al. 1997	Patient concerns form	Y			* More concerns discussed			* less satisfaction	* longer	promising
McCann et al. 1996	PQPL concerns	Unclear	NS (trend only)					NS	* longer	emerging /low
Multiple Interventions with QPL										
Brown, et al. 1999	QPL	Y								
	QPL + coach	Y								
	QPL combined group	Y	* more	* tests (prognosis NS trend)			NS	NS		supported
Brown, et al. 2001	QPL - active Dr	Y	NS	* prognosis		* more than passive QPLs, NS re controls	NS		* shorter	
	QPL - passive Dr	N	NS	* prognosis			* More at post			
	QPL combined group	Mixed	NS	* prognosis	** more-prognosis	NS	NS prior	NS	* longer	promising
Kidd, et al. 2004	Q encouragement	N	NS					NS, * 3 months post		acceptable
	Q identification incl. PQPL	N	NS					NS, * 3 months post		
	Q identification, PQPL, rehearsal	N	NS					NS, * 3 months post		
Thompson et al. 1990	Study 1: Topic List and 3Q PQPL	N	* more				* less	NS	NS	acceptable
	Study 2 Encourage only no PQPL	encouraged	NS				NS	* more		
	QPL	N	NS				NS	* more		
Related multiple interventions										
Middleton et al. 2006	Patient agenda list	Y	** more concerns identified					* 1/4 variables - depth Dr relationship	* longer	acceptable
	Patient agenda list with GP train	Y	** more concerns identified					* 1/4 variables - depth Dr relationship	* longer	

* p<0.05
** p<0.01

Table 2 Literature Overview: Single and Multiple QPL/PQPL Intervention Studies

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Single Interventions and related studies								
Bolman, C. et al.	2005	Long term efficacy of a checklist to improve patient education in cardiology	Randomized control group including longer term follow-up; design issues	Acceptable practice	65 controls, 53 Intervention subjects; data for measures = 59 controls, 46 intervention subjects	Cardiovascular outpatients were recruited at discharge from hospital. Intervention subjects were given a Frequently Asked Questions checklist to complete (49 Qs-10 themes) which they could bring to the outpatient consultations at 1, 4, and 10 months post discharge. Controls received information about a helpline service. The clinician addressed checklist questions if asked but did not actively endorse the checklist. 80% of the intervention subjects completed the checklist for the first visit and 73% used the checklist but use declined for later visits. No differences found re patient reported participation/question asking behaviour. Intervention subjects had less knowledge than controls after the first consultation. Intervention subjects had less state anxiety related to the first visit. Due to attrition there were statistical power issues that precluded effective analysis of the some variables following visits. The checklist appears to have been given or posted to patients up to a month before the visit.	1) 73% Intervention SS used the QPL at first visit 2) Intervention subjects less state anxiety at first visit (p=0.04) 3) Less knowledge than controls after first visit (p=0.00) 4) Shorter duration of first consult for Intervention subjects (p=0.00) but a longer final visit (p=0.022). 5) Participation re question asking is patient reported - no significant difference to controls	Netherlands
Bruera, E.C. et al.	2003	Breast Cancer patient perception of the helpfulness of a prompt sheet vs. general information sheet during outpatient consultation…	RCT	Promising practice	30 QPL subjects, 30 GIS subjects; cancer	A 22 question QPL or a GIS (general information sheet) was provided before cancer outpatient consultations, the QPL was not endorsed. There was no difference in the total number of questions asked although QPL subjects asked more questions about diagnosis (p=0.025). There was no difference in consultation time. QPL subjects rated the information material provided as more helpful than GIS subjects (p=0.01).	1) No significant difference is Qs asked between groups 2) QPL subjects asked more Qs about diagnosis (p=0.025) 3) No significant difference in consultation time 4) QPL subjects rated the information provided as more helpful (p=0.01)	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Butow, P. et al.	1994	Patient participation in the cancer consultation: evaluation of a question prompt sheet.	RCT	Acceptable practice-design issues	142 patients randomized to control or intervention	A QPL or GIS was provided before an outpatient or inpatient consultation with the medical oncologist. QPL subjects were encouraged to ask questions and to generate some Qs of their own on the QPL. The QPL was not endorsed. There was no difference in overall question asking but QPL subjects asked more questions about prognosis. There were no differences in consultation recall or patient satisfaction between the groups. In-patients asked fewer questions but they had prior consultations and it is unclear whether their presence in both groups was equivalent. Only 65% of patients completed the follow–up interviews and surveys. Patients who preferred more active decision making asked more Qs in both groups. Younger, female patients also asked more questions. Period for knowledge recall was variable 4-20 days.	1) No significant difference in total Qs asked 2) more Qs re prognosis(p<0.05) 3) no significant differences for knowledge recall or patient satisfaction	Australia
Clayton, J. et al.	2007	RCT of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care.	RCT	Supported practice	92 QPL, 82 controls	Patients and caregivers randomised to standard consultation or QPL prior to palliative care outpatient consultation. Although all Drs were asked to actively endorse and refer to the QPL the degree of physician endorsement (nil, basic, extended) for QPL subjects was also assessed from the audiotapes. QPL subjects asked more questions, discussed more issues covered by QPL and asked more questions about prognosis and end of life issues. There were no differences between groups re anxiety or patient satisfaction. QPL consultations were significantly longer (7 minutes) than for controls but authors suggest QPL length may impact consultation time. Degree of physician endorsement related to number of questions asked for QPL subjects.	1) Intervention subjects more Qs overall (p<0.001, 2) More Qs re prognosis (p<0.004); 3) More discussion of prognosis (p<0.003) and end of life issues (p<0.001) 4) No differences in anxiety or patient/ physician satisfaction 5) Consult time longer (p=0.002). Degree of Dr rated endorsement related to Qs asked (p<0.0001) for QPL subjects	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Clayton, J. et al.	2012	Physician endorsement alone may not enhance question-asking by advanced cancer patients during consultations about palliative care.	Comparison group, standardised measures. Analysis of data from control subjects in study above	Acceptable practice	80 controls - advanced cancer	Further data analysis concerning the study above - these control subjects did not receive a QPL prior to the consultation. The degree of physician endorsement of question asking by patients (extended, basic, nil) was determined from inter-rater analysis of post-consultation audio tapes. The degree of physician endorsement was not related to the number of questions control patients asked. Control subjects with higher levels of anxiety asked more questions. Control SS with a greater estimated period of survival asked more questions. Control patients who had seen their physician before asked fewer questions. Other demographic variables were unrelated to question asking. Authors conclude that physician endorsement alone, without a QPL, was not associated with an increase in patient question asking. Query whether extended physician endorsement for those without a QPL is the same as for those with the QPL as usually endorsement means the Dr has access to the Qs QPL subjects want to ask at the start of the consultation.	1) Degree of Dr endorsement assessed from audiotape not significantly related to Qs asked for control subjects (not receiving a QPL). See study above.	Australia
Fleissig, A. et al.	1999	Encouraging out-patients to make the most of their first hospital appointment…..	RCT but design/data issues	Emerging practice	Unclear but 1077 patients including controls returned survey, 369 Help Card Intervention	Intervention outpatients received a Help Card (similar to QPL) 2 weeks prior to consultation which suggested 23 questions to ask in the later outpatient hospital consultation. Half the patients who received the Help Card reported it enhanced the consultation but no data concerning whether interventions subjects actually used the card. Generally, no differences between the intervention and control groups were found re question asking although more intervention subjects recalled raising the issue of recurrence. The study design is quite unclear, and only a post follow-up survey was used which also asked subjects to report on issues prior to the intervention and may have been affected by the consultation. The long period (2 weeks) between receiving the Help Card and the consultation may have affected results. Not conclusive.	1) Intervention subjects reported raising the issue of recurrence more than other groups ($p<0.01$) 2) Patient satisfaction was significantly different to control subjects but not significantly different to pre-intervention subjects receiving usual care. 3) Descriptive and suggestive analysis of usability - 50% of intervention subjects report QPL enhanced the consultation.	UK

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Galliher, J.M. et al.	2010	Patients' question asking behaviour during primary care visits: A report from the AAFP National Research Network	RCT but some design issues	Acceptable practice	445 intervention subjects and 389 control subjects across 20 practices	Primary care intervention subjects received brochure about the AM3 intervention, were provided with a leaflet with the 3 Questions and were prompted by nurses to ask the 3 Qs immediately before the consultation. The 3 questions were 1) what is my main problem; 2) what do I need to do about my problem and 3) why is it important for me to do this. Found no differences between groups in Qs asked but the rate of Qs asked was high for both groups suggesting the potential for ceiling effects. No differences between groups in filling or taking prescriptions. Question asking measures are crude counts - no analysis of type of questions asked. Authors discuss potential for a Hawthorne effect and suggest a longitudinal study with baseline data for intervention subjects would strengthen the design. There were differences between the interventions and control groups with regard to ethnicity, marital status and level of education but analyses were adjusted. Authors note that these generic questions are less personalised than for many QPL studies. Some feedback from intervention subjects re the wording of the questions and why they did not ask them much may have been useful.	QPL plus prompting 1) No significant difference in overall Qs asked 2) No significant difference in filling or taking prescriptions	USA
Hamann, J. et al.	2013	Effects of a question prompt sheet on active patient behaviour: A RCT with depressed outpatients.	Randomized comparison group but with design issues.	Emerging practice -as major design issues	51 intervention, 49 controls	100 existing patients with depression at 1 clinic were randomized to an intervention of control group. All patients were seen by the one psychiatrist who was not blinded to membership grouping. Intervention patients received a QPL prior to their next consultation. The QPL, developed by clinicians without patient consultation, contained 15 standard questions including questions about their diagnosis, treatment options, symptoms, and quality of life. The patient could tick those they wished to ask and include other questions of their own. There were no differences in the number of topics raised by the intervention and control groups. This may not be surprising given this intervention is being introduced into an existing doctor -patient relationship and many questions on the QPL may have been previously asked by patients in earlier consultations. It is not comparable to other studies where there is no existing relationship to the consultant. The generalisability of these findings is very limited.	1) No significant differences in numbers of topics raised by intervention subjects vs. controls 2) Generally no significant differences found for 18/19 topics that were actually discussed during the consultations save for somatic illnesses. Methodological issues.	Germany

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Hornberger, J. et al.	1997	Effects of a self-administered questionnaire to enhance awareness of patients' concerns in primary care	RCT: Physicians randomised to implement questionnaire or not.	Promising practice	10 physicians (5 controls, 5 questionnaire); 105 control patients, Intervention: Phase 1 = 49, Phase 2 = 47.	Intervention patients were given a pre-visit questionnaire (patient concerns form - PCF, 31 items) to go through and this was then discussed with the physician at the consultation. Patients and physicians filled out post visit questionnaires on satisfaction. Patients also filled out the SF36 and HADS measures. Audiotapes of the consultations were analysed. There were two phases to the study: Phase 1 involved both control and intervention physicians delivering generic information to allow physicians to get used to the system. The second phase involved intervention physicians discussing PCF while controls continued to discuss generic information. A total of 47 patients received PCF. Intervention visits were 34% longer (increase of 6.8 mins) with most of the time spent in discussing biomedical diagnosis and the physical examination. Diagnostic issues discussed in intervention visits were 30% higher. Only 1 of 4 patient satisfaction items (the Dr's understanding of the reason for the visit) showed a significant difference between intervention subjects and controls and intervention subjects were less satisfied - but authors noted ceiling effects are apparent in the scale.	Endorsed patient concerns checklist: 1) Intervention subjects visits were 34% or 6 minutes longer ($p<0.05$) 2) There was more discussion of diagnostic issues ($p<0.05$) and 3) The physical examination was longer ($p<0.05$). 4) Only 1 of 4 patient satisfaction items showed a significant difference and intervention subjects were less satisfied	USA
King, E. et al. (MAGIC)	2013	The MAGIC programme evaluation	Qualitative evaluation of campaign re Ask 3 Questions	Other - emerging practice	Unclear and depends on area considered	The Magic evaluation (UK) is largely concerned with initiatives concerning clinical training to implement a shared decision making approach in medical consultations. One approach mentioned is focused on patients - The Asking Three Questions initiative - which is really a 3 question QPL. It is suggested that patients are encouraged to ask these 3 Questions in GP consultations. These are: 1) what are my options; 2) what are the possible benefits and risks and 3) how can we make a decision together that is right for me. Although there is some feedback concerning the initiative it is largely about the media strategy for the 3Q initiative and there is very little quantitative data about where the initiative was actually tested and whether in fact the patients asked the three Qs outlined. This initiative uses 3 Q suggested from Sheppard et al. (2011) study, but Sheppard et al.'s data was based on simulated patient interviews. This initiative requires some field testing prior to more widespread implementation	Asking 3 Qs Initiative based on Shepherd et al. (2011) - little quantitative data available in the MAGIC report	UK

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Lim, L. et al.	2011	Doctor-patient communication, knowledge and QPLs in reducing preoperative anxiety; a RCT.	RCT	Acceptable practice	101 intervention; 106 controls	Examined whether use of a QPL prior to surgery reduced pre-operative and post operative anxiety compared to controls. All groups had a reduction in anxiety between initial consultation and 1 day prior to surgery. QPL group showed a trend for greater reduction of anxiety immediately post surgery and a significant reduction at outpatient follow up. For all patients a reduction in anxiety was associated with patient satisfaction with the consultations and the Dr's ability to answer questions and the authors noted that the Dr's interpersonal skills appeared to far outweigh the usefulness of the QPL.	QPL group showed a trend (p<0.10 N.S.) for a greater reduction in state anxiety immediately post surgery and there was a significant difference at follow-up (p<0.05).	Singapore
Maly, R. et al.	1999	A RCT of facilitating information giving to patients with chronic medical conditions: effects on outcomes of care	RCT – design issues	Emerging practice	265 family medicine patients but only 205 at follow up	Used a QPL which asked patients to identify and write down two questions to ask their doctor. Used on 2 occasions. Endorsed by doctor. Intervention subjects also saw their medical record progress notes. Controls asked to write down 2 suggestions for clinic improvement and were given a health education sheet. Randomisation by card shuffle. Found a significant difference for increased satisfaction for the experimental group after adjusting for covariates (p=0.045) and no significant difference for consultation length. After the intervention experimental group reported slightly better physical functioning (p=0.005) and improved overall health status (p=0.001) but one queries whether this effect on their self-report ratings may be associated with the increased attention vs. information they received.	QPL group 1) Increased patient satisfaction (p=0.045) 2) No difference in consultation length 3) Small improvement in physical functioning and self-reported health status compared to controls (p<0.01)	USA
McCann, S. et al.	1996a,b	Encouraging patient participation in GP consultations: Effect on consultation length and content; patient satisfaction and health	RCT	Acceptable practice (patients from only 1 GP)	120 (59 = intervention, 61 = controls)	Patients of a single doctor were provided either a 'Speak For Yourself' leaflet or a dietary advice leaflet. Intervention leaflet asked patients to think about their problems, causes and treatment, encouraged them to ask Qs about diagnosis and treatment and they were provided space to list their concerns. Intervention group patients had 17% longer consultations (p< 0.05) and asked on average 0.89 more questions (p<0.10). No information was provided on the types of questions asked. There was no effect on patient satisfaction or number of GP visits in the subsequent year. The GP felt they understood patients better. Overall there was no effect on SF36 scores, although younger and higher SES patients in the intervention group improved more than the same group among control patients. The second paper (b) reiterates much of the above but found	Leaflet and PQPL (concerns) 1) Intervention subjects on average asked 0.89 more questions (p<0.10) - NS, trend only 2) Intervention subjects had longer consult time (p<0.05) 3) No effect on patient satisfaction	

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						locus of control and self-efficacy scores were not helpful in predicting outcomes.		
Martinali J. et al.	2001	A checklist to improve patient education in a cardiology outpatient setting	RCT	Acceptable practice - some design issues	53 Intervention subjects; 50 controls	Intervention subjects received a 49 item QPL and a CAD information brochure 1 week prior to the consultation whereas controls received just the brochure. The consultation was mid way during the course of treatment. State anxiety immediately before the visit was lower for intervention subjects (p=0.02) and there were no differences in patient satisfaction or the length of consultation between the groups. Only 75% of intervention subjects completed their checklists prior to the intervention. Of those that did 47% indicated that it had not resulted in greater exchange of information although 38% thought it had. 71% of intervention subjects thought they would use it again for their next visit.	1) Intervention subjects lower anxiety pre-visit (p=0.02) 2) No differences re patient satisfaction or consultation length	Netherlands
Shepherd, H.L. et al.	2011	Three questions the patient can ask….	Cross-over trial using standardised simulated patients	Promising practice	18 simulated patients asking 3 questions, 18 controls	Tested the effect of 3 basic questions for patient consultations (what are my options; what are the benefits and harms and how likely are these) on information provided by 18 GPs during treatment consultations. Used a cross-over trial with standardised patients simulating mild to moderate depression. Used ACEPP (assessing communication about evidence and patient preferences) and Option tools to analyse information provided and patient involvement from the audio-taped consultations. Data showed the intervention simulated patient received more information from GPs (p<0.01) when 3 simple questions were asked and the consultation reflected greater GP consideration of simulated patient preferences.	Analysed asking 3 Qs QPL with simulated patients. 1) QPL simulated patients received more information from the GP (p<0.01) 2) the consultation audiotapes reflected greater GP consideration of simulated patient's involvement preferences.	Australia
Shirai, Y. et al.	2012	Patients' perception of the usefulness of a QPS for advanced cancer patients when deciding the initial treatment: a randomized, controlled trial.	RCT	Promising practice	32 intervention; 31 controls	Intervention subjects received 53 item QPL and hospital information sheet (HIS) and controls received HIS only - randomised allocation. No difference in total question asking, or by content area, between the groups but intervention subjects rated the QPL as more useful for asking questions, more useful for understanding the treatment plan and they were more willing to use QPL materials in future.	No significant differences found for total question asking or by content area	Japan

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Smets, E. M. et al.	2012	Addressing patients' information needs: a first evaluation of a question prompt sheet in the pre-treatment consultation for patients with oesophageal cancer.	RCT - small sample	Acceptable practice	17 intervention; 11 controls	Intervention subjects received a 38 question QPL (modified from previous research) immediately prior to second consultation for oesophageal cancer - the first consultation was for initial intake and to schedule necessary investigations. Intervention subjects marked questions they wished to ask and this was handed to clinician - controls did not receive QPL. Intervention patients asked significantly more questions particularly about treatment aspects/ procedures. No differences between groups for length of consultation or patient satisfaction,	1) Asked more Qs overall (p<0.01) and particularly about treatment aspects/procedures (p<0.01). 2) No differences between groups in length of consultation or patient satisfaction	Netherlands
Multiple Interventions								
Brown, R. F., et al.	1999	Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking.	RCT: Comparison group and controls	Supported practice	QPL 20; QPL plus coach 20; controls 20	Examines 2 interventions to promote patient participation in the cancer consultation - the use of a 17 question QPL and the QPL combined with coaching re asking questions. Presentation and discussion of QPL significantly increased the number of questions asked during the consultation. Coaching did not add to the effects of the QPL. Psychological outcomes did not differ between groups. Authors suggest QPLs are an effective and inexpensive intervention to enhance patient participation. Suspect limited statistical power for some analyses as the sample is small.	Multiple interventions: QPL and coaching plus QPL 1) QPL groups combined asked more questions overall (p=0.043) and concerning tests (p=0.048) 2) No significant differences in Qs asked between the 2 QPL interventions 3) Trend only concerning more prognosis Qs for QPL combined (p=0.09) 4) No significant differences re state anxiety 5) No significant differences re patient satisfaction	Australia
Brown, R. F. et al.	2001	Promoting patient participation and shortening cancer consultations: a RCT.	RCT: Comparison groups and controls	Promising practice	Controls 158; Passive Dr & QPL 79; Active Dr & QPL 81	Compares those given a 17Q QPL prior to the consultation to controls. Of those given QPLs 2 groups - active and passive responding by the consultant. There were no differences in total question asking between these groups or controls. However, patients given QPL asked more questions about prognosis and received more prognostic information. Patients receiving QPLs overall had longer consultations and higher levels of post consultation anxiety. Authors state that when clinicians actively addressed the QPL anxiety was reduced, consultation duration was reduced and consultation recall was increased. Note for the active QPL condition there was a difference to passive QPL condition re knowledge recall but no difference to controls. Gender differences are noted in these effects - men recalled more information in the active Dr condition. No	Multiple interventions re QPL.1) Overall, no significant difference in total Qs asked between active and passive Drs or between QPL interventions combined and controls; 2) QPL groups combined asked more prognosis Qs (p=0.004) 3) QPL combined had longer consultation times but there was a significantly shorter consult time for Active Dr QPL (p=0.02) compared to other groups. 4) Active QPL condition subjects had better knowledge recall overall (p=0.036) and concerning treatment (p = 0.01) than passive QPL group but no difference to controls 5)	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						differences found re patient satisfaction.	No differences in state anxiety prior to consultation but passive QPL subjects had higher anxiety following consultation 6) No differences in patient satisfaction between groups	
Gattellari, M. et al.	2001	Sub-analysis RCT component, prospective, pre-post	Acceptable practice		233 cancer patients	This is a sub-analysis of RCT data which is not clearly identified but it is assumed this is from Brown et al. (2001). As part of this study preferred shared decision making style, preferences concerning informational and emotional support and state anxiety scores were obtained from all intervention and control subjects prior to the consultation. This data was examined in relation to the perceived achieved SDM role in the consultation and other follow-up measures of state anxiety, knowledge recall and patient satisfaction. There was a match between preferred and perceived SDM for 34% of patients, with 29% more active than desired and 37% less involved than desired and extent of disease was a significant predictor for less involvement than desired. Perceived role, but not role mismatch, predicted patient satisfaction with the consultation and the perceived amount of informational and emotional support received from the Dr. Patients who reported a shared role in the consultation were most satisfied and those that reported that either they or the doctor had exclusively made the decision were least satisfied. No differences in recall were related to the perceived SDM role. Differences in question asking related to SDM are not reported save for a sub-sample of patients with incurable disease where patient perceptions of involvement in decision making were not associated with amount of question asking. Some, but not comprehensive, checks to assess whether there was potential confounding by intervention type.	SDM (including QPL intervention) study which briefly examined differences relating to patient ratings of involvement in the consultation 1) For a sub-sample of patients with incurable disease the patient perceptions of involvement in decision making were not related to question asking 2) Perceived role was a predictor for patient satisfaction and the perceived amount of informational and emotional support received from the doctor 3) Patients who reported a shared role were the most satisfied	

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Kidd, J. et al.	2004	Promoting patient participation in consultations: A RCT to evaluate the effectiveness of 3 patient focussed interventions	RCT - design issues	Acceptable practice	Encouragement = 38, Q identification = 42, Q Identification and rehearsal = 35; Attention control = 40, Control = 47	Examined 3 very brief interventions to facilitate QA (encouragement, question identification PQPL, and question identification with rehearsal. No differences in total question asking found between intervention subjects and controls but immediately after the intervention participants in the intervention groups reported higher levels of self-efficacy in asking Qs of Drs than did controls. Level of patient satisfaction were similar across groups immediately after the consultation but there was a significant difference at 3 months post index consultation with levels of patient satisfaction declining for the controls . The question asking by all groups including controls was high raising issues concerning potential ceiling effects and there was no analysis of questions by content type or question intent.	Question asking facilitation interventions & PQPL: 1) No differences in total Qs asked 2) At follow up Intervention subjects reported higher levels of self-efficacy is asking questions of doctors than did controls (p<0.05)	UK
Middleton, J.F. et al.	2006	Effect of patient completed agenda forms and doctors' education about the agenda on the outcome of consultations: randomised controlled trial	Embedded cluster RCT- implementation issues	Acceptable practice	46 GPs and 976 consultations	46 GPs (15 = control, 31 = education intervention). Control GPs had 480 appointments, half using agenda form, half not. Education GPs had 496 appointments, half with form, half not. Patients allocated to consultations using the agenda completed a patient agenda form immediately prior to the consult and this was given to the Dr. The agenda form asks patients the reason for the consultation, their expectations of it and to list their concerns. The number of problems identified in consults increased by 0.2 (p=0.007) with the agenda form, 0.3 with GP education (p=0.005) and 0.5 with both (p<0.001). Consult length increased by 0.9 minutes with agenda form and 1.9 minutes with agenda form and GP education. One element of patient satisfaction (depth of Dr patient relationship) increased with the use of the agenda form. The patient agenda form is not clearly outlined or provided in the article.	Dr use of a patient agenda form (similar to a PQPL): 1) Significant (but small) increases in patient problems identified with agenda use. 2) Slightly larger (but still small) significant increases in problems identified with agenda use and GP training 3) Small but significant increases in consult time for both of the above (up to 2 mins) 4) the depth of the Dr-patient relationship was the only patient satisfaction element to reach significance	UK
Smith, S. et al.	2010	A decision aid to support informed choices about bowel cancer screening among adults with low education: RCT.	RCT	Acceptable practice	384 intervention subjects (combined); 188 controls	This study is about the use of a patient decision aid to assist decisions concerning bowel cancer treatment for those likely to have lower literacy levels (e.g. targeted the socially disadvantaged) and it was found to increase knowledge and informed choice and to lessen decisional conflict. However, the participation rate for screening was reduced in the intervention subjects (59%) vs. controls (75%). Of interest was that there were 2 decision making intervention groups and one of these received a QPL as well the decision aid. However, as there were no differences in the results for the 2 decision making	Multiple interventions - Use of patient decision aid with and without QPL. No added benefit of QPL in patient decision aid intervention	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						intervention arms the data was combined. Thus the addition of the QPL as part of a decision making intervention appeared to provide little additional benefit. The study raises the important issue of addressing literacy levels in the development of QPLs and pDAs but in this study no actual assessment of the literacy of the subjects was undertaken. A commentary by Von Wagner et al (2010) raises the issue as to whether the use of telephone calls in recruitment and follow up may have influenced decision making and may be atypical practice. This controversial paper raises implications of the value of decision aids in the screening context.		
Thompson S.C. et al.	1999	Patient oriented interventions to improve communication in a medical office visit	RCT -design issues	Acceptable practice	Study 1: 53 patients; controls = 24, intervention A = 29. Study 2: 49 patients; Controls = 18, intervention B = 13, intervention C = 18.	Obstetric/Gynaecology patients recruited from private practice waiting room were asked to participate in two linked studies. Study 1: Intervention A patients were given a list of health concerns and asked to write down 3 questions for the physician and to bring them into the visit. Controls received a questionnaire about the waiting room. Both groups were then given self-report measures to do later at home (this included how many questions they asked and satisfaction). Visits were timed and physicians filled out self report measures as well. Physicians were unaware of group allocation. Permission to do audiotapes was not given. Results were positive but it was not known if more questions came from feeling they had permission to ask questions rather than formulating questions. Study 2 attempted to address this. Study2: Intervention B subjects were given a checklist of information patient should obtain, rather than a concerns list, and asked to develop 3 questions to ask as for Intervention A. Intervention C patients were told that the doctor encouraged questions but they were not given a checklist or asked to write down questions. They filled out a questionnaire about the waiting room. Controls all filled out a questionnaire about the waiting room. All groups filled out self report measures afterwards at home. Visits were not timed and physicians did not fill out self report measures. Authors felt health topic list was more effective than checklist in eliciting questions, probably because of its broader focus.	Study 1: The intervention A group asked more questions than the control group ($p<0.05$). Study 2: There was no difference between intervention B & C groups on how many questions they asked. Both intervention groups asked more of the questions they wanted to ask compared to controls ($p<0.05$) but there were no significant differences in total questions asked compared to controls. Data from study 1 and study 2 were combined for analysis and a trend ($p<0.07$) was found for anxiety and patient satisfaction but not for total questions asked. Experimental subjects had less anxiety and higher patient satisfaction than controls. Satisfaction with the visit was not related to number of questions asked or having asked all the questions patients wanted to ask. Patients recall of information was more accurate when they asked more questions ($p<0.05$) and when they asked more of the questions they wanted to ask ($p<0.05$).	USA

Table 3 Summary of Findings: Combined Intervention Studies

First author	Intervention type	Endorsed Y/N	Total QA	Content/type QA	Information given	Knowledge Recall	Anxiety	Patient Satisfaction	Consult Time	Strength
Albada, A. et al. 2012a	Web info & PQPL	Y	NS		* risk * prevention				NS	Promising
Albada, A. et al. 2012b	Web info & PQPL	Y				* recall …… *cancer knowledge				Promising
Ambler, N. et al. 1999	Advocacy & QPL	advocated					NS immediately post * 1 group at later follow-up	NS		Emerging
Anderson, H. et al. 2001	Workbook & QPL	encouraged							NS	Emerging
Bozic, K. et al. 2013	Video, booklet, & PQPL	Y	** (Dr rated)							Acceptable
Brown, R. F. et al. 2004	Video, booklet & QPL	N	NS		** more		* less prior, but variable post	NS		Promising
Butow, P. et al. 2004	Booklet & QPL	encouraged	** more	* more challenge Q			* before, NS after			Promising
Cegala D. J., et al. 2000	Training, booklet and QPL	encouraged	** more		** more					Promising
(see above)	Summary leaflet	N	NS		NS					
Finney, J.W. et al. 1999	Coaching and QPL	encouraged	NS concerns		** more			NS (trend only)		Acceptable
Kim, Y. M. et al. 2003	Coaching and QPL/PQPL	encouraged	** more; *more concerns							Acceptable
Lewis, C.C. et al. 1991	Coaching and PQPL	encouraged				** more recall	NS	* children more; NS parents		Acceptable
Mishel, M.H. et al. 2002, 2003	Coaching, Liaison & QPL	encouraged				NS cancer knowledge				Acceptable

First author	Intervention type	Endorsed Y/N	Total QA	Content/type QA	Information given	Knowledge Recall	Anxiety	Patient Satisfaction	Consult Time	Strength
Mishel, M.H et al. 2009	Coaching & QPL	encouraged			* self-report	** cancer knowledge				Acceptable
Roter, D. L. 1977	Coaching & PQPL	encouraged		* more direct Qs, less indirect			** more at post	* less[1]	NS	Promising
Roter, D.L 1984	Coaching and PQPL	encouraged		* diagnosis, prognosis, lifestyle						Promising
Sander, R.W. et al. 1996a	Health Card/QPL	encouraged	* more			NS				Acceptable
Sander, R.W. et al. 1996b	Coaching and QPL	encouraged	** more			** more recall				Acceptable
Sepucha, K.R. et al. 2000	Pre-consult planning with active, PQPL & passive facilitation	facilitated							NS	Emerging
Sepucha, K.R. et al. 2002	Consultation planning and PQPL	encouraged						* more		Emerging
Tabak, E.R. 1998	Education booklet and QPL	encouraged	NS (power issue)					NS		Emerging
Tennstedt, S.L. 2000	Patient activation and QPL	N						* more		Emerging
Van Weert, J. C. et al 2011	Nurse education and QPL	encouraged	* more	* treatment	see discussion	* more recall 2 items			NS Trend more	Emerging

1. Roter (1997) reports significantly less satisfaction for the intervention group but the presentation of the mean data is confusing causing Kinnersley et al. (2007) to conclude, possibly mistakenly, that intervention subjects reported greater satisfaction

* $p<0.05$

** $p<0.01$

Table 4 Literature Overview: Combined Intervention Studies

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Literature concerning Combined Interventions								
Albada, A.	2010	Preparing for breast cancer genetic counselling: Web-based education for counselees	Various studies	NA -refer individual studies	see below	Compendium of articles from the Albada thesis. Reports on a pre-visit website to be used by people requesting genetic counselling for breast cancer. Studies report the use of the pre-visit website in conjunction with a PQPL for genetic counselling - refer to the studies below.	NA -see studies below	Netherlands
Albada, A. et al.	2012a	A pre-visit website with question prompt sheet for counselees facilitates communication in the first consultation for breast cancer genetic counselling: findings from a RCT.	RCT - design issues	Promising practice	102 intervention, 90 controls	Intervention subjects used a pre-visit web site and were given a PQPL where they wrote the questions they wished to discuss and this was endorsed by the counsellor - controls received usual care which was a leaflet about the consultation. Outcomes were assessed using the audio-taped consultations. Intervention subjects did not ask more questions than controls. However intervention subjects more often shared their agenda and directed the communication and paraphrased the counsellor's words. Counsellors provided more information to intervention subjects than controls - related to their PQPL - mainly concerning risk and preventive options. No differences found re consultation duration. Hard to disentangle effects of the website and the PQPL component; counsellors could not be blinded, and audiotape raters could detect group allocation due to mention of PQPL in intervention consultations. Authors suggest a QPL may have facilitated more question asking.	Combined intervention: web information and QPL 1) No significant difference in QA 2) Detected differences in patient communication style elements ($p<0.03$-0.01) which may have resulted in intervention subjects receiving more information 3) Intervention subjects received more information re risk and preventive options ($p<0.05$) 4. No significant differences in consultation time	Netherlands
Albada, A. et al.	2012b	Effects of a pre-visit educational website on information recall and needs fulfilment in breast cancer genetic counselling, a randomized controlled trial.	RCT - design issues	Promising practice	103 intervention, 94 controls	Assessed the effects of a pre-visit website and QPL for breast cancer counselees. Intervention group had higher level of recall of information from the consultation and greater post visit cancer and heredity knowledge than controls. Hard to disentangle any effects of QPL from web education intervention. Also lack of blinding of counsellors re group membership.	Combined intervention: web and QPL 1) Greater recall of information ($p= 0.02$) 2) Greater post visit cancer knowledge ($p=0.03$)	Netherlands

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Ambler, N. et al.	1999	Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: Comparing advocacy with a conventional approach	Action research; Pre/post and 6 month follow-up	Emerging practice	66 conventional model, 37 advocacy model subjects	Advocacy care model involved nurse counsellor helping patients develop questions - PQPL, accompanying patient in consultation and if necessary ensuring questions were asked. Some counselling after consult and then as needed contact. The conventional method was not explained but they appeared to have a longer post consultation counselling phase. The study was not able to draw conclusions about the effects of the advocacy methods using standardised scales re anxiety, depression and symptoms (no differences between groups) but visual anolog scale items indicated that advocacy intervention patients rated themselves as being better informed, had a better understanding of treatment options and considered themselves more informed in decision making but the actual data is not presented. This is a combined intervention which doesn't investigate the effect of asking questions or PQPL.	Combined intervention: advocacy and PQPL. Suggestive findings only 1) More positive ratings re consultation SDM elements for advocacy/PQPL subjects	UK
Anderson, H. et al.	2001	Evaluation of the Chemotherapy Patient Monitor: an interactive tool for facilitating communication between patients and oncologists during the cancer consultation.	Pilot testing of QPL style tool	Emerging practice	initial study 24; audit study 34	The Chemotherapy Patient Monitor is a workbook with a checklist or QPL of side effects of chemotherapy for advanced colorectal cancer patients. The initial consultation was a baseline consult and the CPM was used in 2 subsequent consultations - the patient completed it immediately prior to these consultations and it was endorsed by the clinician. All patients understood the CPM and 92% felt it improved visits, 83% oncologists found it useful and consult time was not increased for 82% of visits	Combined intervention, workbook and QPL/PQPL - consultation time not significantly increased for Chemotherapy Patient Monitor	UK
Aranda, S. et al.	2012	Impact of a novel nurse-led pre-chemotherapy education intervention (ChemoEd) on patient distress, symptom burden, and treatment-related information and support needs trial.	RCT - longitudinal elements	Acceptable practice	98 intervention, 94 controls; mixed cancer patients	The ChemoEd intervention included DVD, QPL, self-care information and a pre-consultation education session <24 hours before the consultation. Also included telephone follow-up after first treatment (Intervention 2) and interview after second treatment (Intervention 3).Measures were taken at Time 1 before education intervention and immediately prior to the first (Time 2) and second chemotherapy treatments (Time 3). The pre-chemotherapy intervention did not reduce patient distress but appeared to reduce patient concerns at Time 3 compared to controls. The education program included a QPL but any effects/ use of QPL not discussed	Combined intervention DVD; QPL; education and information. 1) Pre-treatment intervention did not reduce patient distress before treatment 2) Intervention appeared to reduce patient concerns by second chemotherapy session compared to controls. This study did not assess QPL component directly	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Bozic, K. J. et al.	2013	Shared decision making in patients with osteoarthritis of the hip and knee: results of a RCT.	RCT	Acceptable practice	95 interventions subjects and 103 controls	The SDM intervention was a digital video and book describing treatment alternatives for hip and knee osteoarthritis and a structured list of questions (PQPL) which patients developed with a health coach and provided to the surgeon. Controls received general information about the surgeon's practice. The primary outcome tracked whether patients reached an informed decision during their first visit. Significantly more intervention subjects reached an informed decision at the first visit and they had more confidence in knowing what questions to ask their doctor. Surgeons rated the number and appropriateness of questions higher in the intervention group. As patient derived PQPL is only part of the intervention it is hard to assess its particular effects. Some issues re reliance on self-reported outcome measures.	Combined SDM intervention which included QPL, video and book: 1) More intervention subjects reached informed decision during the first visit (p=0.005); 2) More and better patient Qs asked as rated by surgeon (p=0.0001); 3) Post-interventions subjects reported more confidence in asking Qs (p=0.0034)	USA
Brown, R. F. et al.	2004	Education and role modelling for clinical decisions with female cancer patients.	RCT	Promising practice	30 Intervention subjects, 35 Controls	The intervention pre-consultation package included a video and a SDM booklet which included suggested questions to ask the Dr (QPL) whereas controls received a Living with Cancer booklet. Patients completed questionnaires immediately prior to, immediately post consultation, 2 weeks and 6 months post consultation. Although no difference in total questions asked intervention subjects were more likely to declare their information and treatment preferences (p<0.01) and their perspectives on costs, benefits (p<0.05) and side effects. Drs introduced more new themes in intervention consultations (p<0.01). No significant differences in patient satisfaction between the groups or concerning decisional conflict after treatment and at 6 months follow-up.	Combined intervention - information package with QPL Intervention. 1) Intervention subjects more likely to state information and treatment preferences (p<0.01), and their perspectives on costs and benefits (P<0.05) 2) Drs introduced more new themes with these subjects (p<0.01) 3) Intervention subjects less anxiety at pre-consultation and longer term follow-up but not immediately post consultation 4) No differences re total Qs asked 5) No significant differences re patient satisfaction 6) No differences in decisional conflict at 6 months follow-up	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Butow, P. et al.	2004	Cancer consultation preparation package (CCCP): changing patients but not physicians is not enough.	RCT	Promising practice	80 CCPP intervention; 80 controls; cancer patients	For the intervention group the Cancer Consultation Preparation Package contained a QPL, booklets on clinical decision making, EBM and patient rights, and a clinic introduction leaflet whereas controls only received the clinic introduction leaflet up to 2 days prior to the consultation. Measures at pre-consult, post- consult and 1 month later. Patients receiving CCPP asked more questions and challenged the physician more. Family members rated the CCPP package as more useful than the control booklet. Intervention patients were more anxious immediately prior to the consultation than controls but not at post consultation. Questions about EBM did not increase nor did the provision of EBM information. Fewer CCPP patients believed they had achieved their preferred decision making style (22% vs. 35%; p=0.06, trend). Authors suggest concomitant training of clinicians is required to make CCPP more effective. Note receipt of materials was over 48 hours before intervention and authors noted a higher rate of question asking for Intervention subjects than for other studies.	Combined intervention, Information Package & QPL - 1) Intervention subjects more anxious than controls before consultation (p=0.04) but no difference at follow-up 2) They asked more questions (p=0.005) 3) Challenged the Dr more (twice vs. once; p=0.05) 4) Family members rated CCCP package as more useful than control booklet (p=0.004)	Australia
Cegala D. J., et al.	2000	The effects of communication skills training on patients' participation during medical interviews	RCT	Promising practice	25 GPs and 150 patients	A study to examine dyadic communication between general practice patients and doctors and to examine patient communication contributions in 3 conditions - trained, informed, control/no intervention. Trained patients receive a work booklet 2-3 days before the consultation which included information, examples and prompts to ask and list questions (PQPL) and symptoms. Informed subjects received a brief information summary immediately prior to the intervention. Trained subjects asked more Qs (M=4.46) than informed (M=3.36, p=0.02) or control subjects (M=3.06, p=0.0005). Analysis of Dr's communication indicated that trained subjects obtained more information than informed or control subjects (both, p<0.0001) and trained patients provided more information in the consultation. Dyads consisting of trained patients had a more patient-controlled style of communication than other dyads. Note there are no significant differences found between the 'informed' (leaflet) condition and controls. Study uses a far more refined schema re question asking and differentiates between type and intent of QA and examines interaction factors.	Combined and multiple interventions - training, booklet and PQPL 1) 'Trained' subjects more medical Qs asked than 'informed' (p=0.02) or control subjects (p=0.0005) 2) Trained subjects obtained more information than 'informed' or control subjects (p<0.0001) 3) Trained patients provided more information than 'informed' (p=0.008) or control subjects (p=0.03) 4) No significant differences between 'informed' intervention subjects and controls	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Davison B. et al.	1997	Empowerment of men newly diagnosed with prostate cancer	RCT	Acceptable practice	30 Intervention subjects; 30 Controls; from 2 clinics	A pre-consultation coaching intervention about patient's information needs which also included QPL, an information pack with instructions about how to find answers to their questions and the patients were also encouraged to ask for an audiotape of the consultation. Controls received the general information pack. All subjects completed pre-treatment questionnaires concerning preferred decisional role, anxiety and depression and again at 6 weeks most intervention. Their actual consultation behaviour during the consultation was not directly assessed (e.g. QA, SDM behaviours etc). Results indicated that intervention subjects reported assuming a significantly more active role in treatment decision making. Although their state anxiety was higher than controls prior to the consultation their state anxiety was less than controls at follow-up. May have been useful to also have measures that directly assessed active participation during the actual consultation. QPL is part of a combined intervention.	Combined intervention coaching with QPL 1) Intervention subjects reported assuming a more active role re SDM within consultation ($p<0.01$) 2) Intervention subjects had less state anxiety at follow-up ($p<0.01$)	Canada
Davison B. et al.	2002	Feasibility of using a computer assisted intervention to enhance the way women with breast cancer communicate with their physicians	RCT	Acceptable practice	373 intervention subjects and 376 controls	Intervention subjects used a computer program to identify decision making control preferences and to assess their information needs (computer generated PQPL) and were then coached how to use this information in the consultation to gather information. Controls completed paper version of control preferences scale and had a general discussion with the nurse. Levels of involvement and decision making and satisfaction were measured by survey post -consultation. The majority of women in both groups assumed their preferred roles in the consultation (80%) but more intervention subjects reported playing a more passive role than intended ($p<0.0001$). Both groups reported high levels of satisfaction. A number of design issues are reported by the authors including the fact that many women were not actually preparing for a consultation that required a treatment decision.	Combined intervention with coaching and computer generated PQPL but mainly concerns decision making preferences and whether these were achieved (80%)	Canada

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Deen D. et al.	2011	Asking questions: The effect of a brief intervention in community health centers on patient activation	One group, pre-post testing	Emerging practice	252 general practice patients	Although programs designed to provide patients with questions to ask during medical visits have been developed (QPL), questions that do not arise spontaneously from patients may not provide the questioner with the information of greatest import and may generate answers not tailored to the level of understanding or needs of the patient. Evaluation of the impact of a patient activation intervention (PAI) focused on building question formulation skills and developing a PQPL prior to their physician visit. Level of patient activation and patient preferred role were examined using the self-report patient activation measure (PAM) and the patient preference for control (PPC) measure. One-third of participants moved from lower levels of activation to higher levels (PAM levels 3 or 4) post-intervention. Paired-samples t-test revealed a statistically significant increase from pre-intervention to post-visit PAM scores. Patients preferring a more passive role had lower initial PAM scores and greater increases in their post-intervention PAM scores than did those who preferred a more active role. Patients exposed to the PAI demonstrated significant improvement on a measure of activation. The PAI may be useful in helping patients prepare for more effective encounters with their physicians. No control group and the use of only self-report measures limit these findings.	Combined intervention: Coaching and PQPL 1) Increased patient activation as measured by the self-report Patient Activation Measure ($p<0.01$) and 2) Increased patient preferences for control/ participation in decision making ($p<0.01$)	USA
Finney, J.W. et al.	1990	Promoting parent-provider interaction during young children's supervision visits	RCT: design issues	Acceptable practice - sample small	32 mothers and their babies randomised to coaching (16) or control (16)	Compared coaching intervention and prompting to ask questions/ identify concerns (PQPL) prior to health supervision visit vs. controls that experienced a general discussion of similar length. Participants were predominantly low SES. While parents in both groups identified a similar number of questions/concerns before the appointment (prompted = 1.3; control = 1.8), prompted parents asked 90% of their identified questions and control parents asked 66%. Consultations with prompted parents resulted in an average of 19.5 topics discussed, which was significantly higher than the average of 16.1 topics during consultations with control parents. The authors concluded that parents were successfully prompted to initiate communication about their child's health with their health care provider.	Combined intervention: coaching and PQPL 1) no differences in concerns identified 2) prompted parents asked 90% of their identified Qs compared to 66% for controls 3) consultations with prompted parents resulted in 19.5 discussion topics vs. 16.1 for controls ($p<0.05$)	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Hendren, S. et al.	2010	Study protocol: A RCT of patient navigation-activation to reduce cancer health disparities	Study protocol	NA	178 intervention subjects; 166 controls	This is an outline of a study that aims to reduce the disparities associated with lower SES and minority group membership that are known to occur in cancer treatment. The intervention included a patient navigator and also included a patient activation component. The patient navigators from the community received a training program and their role was to provide tailored assistance including phone calls and meetings and to provide behind-the-scenes coordination of care. It is thought this would have the potential to reduce delays in care, overcome barriers in accessing care and improve patient adherence to the treatment plan. The activation component included the navigator creating a PQPL with the patient and rehearsing question asking with the patient. Although this study commenced in 2010 there appears to be no follow-up data published as yet although it would be interesting to know whether the question asking rehearsal and PQPL components of the intervention led people from disadvantaged backgrounds to ask more question. This paper is included in the review by Henselmens et al.	Combined intervention with QPL aiming to address racial disparities - no data available	USA
Kim, Y. M. et al.	2003	Increasing patient participation in reproductive health consultations	RCT	Acceptable practice	768 women across 64 clinics. Intervention 128 new patients and 256 continuing patients; Controls 128 new patients and 256 continuing patients	Patients were new or continuing patients attending clinics for family planning consultations in Indonesia. Intervention subjects received coaching about asking questions, expressing concerns and seeking clarification and a leaflet to identify questions. Controls received leaflet on HIV/AIDs in a session with educator who also answered any Qs the patients might have about the 'control' leaflet. All consultations were audio taped. Intervention subjects asked more questions (6.3 vs. 4.9) and expressed more concerns (6.7 vs. 5.4) and there were no differences concerning seeking clarification of terms. Differentiates between asking questions for information vs. to clarify terms.	Combined coaching intervention with QPL. prompted PQPL: 1) Intervention subjects asked more questions ($p<0.01$)and 2) expressed more concerns ($p<0.05$)	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Lewis, C.C. et al.	1991	Increasing patient knowledge, satisfaction and involvement: Randomised trial of a communication intervention	RCT -some design issues	Acceptable practice	81 intervention subjects; 60 controls	This is a multiple and combined intervention for children, their parent and Drs prior to a paediatric consultation. The child intervention includes a video tape about communication, a workbook to encourage QA and to identify and write down questions (PQPL) and coaching and rehearsal in question asking. The parent sees only a communication video. The clinicians also received training and a communication video. Controls received equivalent materials not associated with the intervention. Intervention children recalled more medical recommendations, reported greater patient satisfaction and a preference for a more active role. Intervention Drs more often included children in discussion about medical recommendations but there was no difference in physician satisfaction across groups. No differences between parents were found across groups for patient satisfaction or anxiety. Because this is a multiple intervention the discussion is unclear concerning which component of combination thereof accounted for the significance of the observed effects. Although PQPL used no data is provided re whether there was an increase in QA in intervention group although more child utterances were made.	Combined intervention coaching & PQPL: 1) Intervention children had greater recall ($p<0.01$) concerning medication and had higher patient satisfaction ($p<0.05$). 2) No significant differences in satisfaction across groups for doctors or parents	USA
Masters, S. J. et al.	2012	Coaching older adults and carers to have their preferences heard (COACH): A RCT in an intermediate care setting.	Outline of RCT in progress	Other - research outline	230 patients	An outline of a coaching intervention that included a QPL prior to geriatric consultation concerning preparation for care transitions for elderly patients. Transition Care patients (following acute hospital episode) were randomly allocated to either the coaching intervention or to the control group who received usual care. Study in progress - no findings reported.	NA - study in progress	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Mishel, M.H. et al.	2002 and 2003	Helping patients with localised prostate carcinoma manage uncertainty and treatment side effects	RCT – longitudinal - some design issues	Acceptable practice	239 prostate cancer patients. Afro-American and Caucasian	Discusses 2 broad 'uncertainty management' psycho educational and communication interventions for prostate cancer patients delivered by the nurse over the telephone. The intervention arms included the development of PQPL prior to the next consultation .The difference between the 2 intervention arms is unclear but the supplemented intervention also involved a family member. Most analyses combined data from both intervention arms when compared to the controls. Data was collected at 3 times-pre consultation/study entry, 4 weeks (post consult) and at 3 months (after treatment had commenced). There was no evidence found to establish a benefit for either (self-report) patient to provider communication or cancer knowledge during the course of the trial although these were major areas of concern identified by patients. The interventions improved cognitive restructuring (p=0.009) and problem solving (p=0.005) skills for intervention patients for the first 4 months on the intervention and this was associated with some changes in the management of treatment side effects such as urine flow. A follow up study using the same data examined the effects of moderator variables in relation to an uncertainty management intervention. Men's level of education, amount of sources of information and extrinsic religiosity (religious group membership) were found to be significant moderator variables influencing some outcomes of the intervention. Those with low education levels had a greater increase in cancer knowledge from baseline. Subjects with fewer sources of information benefitted more in communicating with nurses and other healthcare professionals but only after some time. Intervention subjects with low levels of religious participation benefitted from the intervention in relation to an increase in patient to provider communication.	Combined intervention training and PQPL: 1) No effect on cancer knowledge 2) No differences to controls re patient to provider communication 3) Significant improvement in cognitive restructuring (p=0.009) and problem solving skills (p=0.005) for intervention subjects and significantly different scores to controls until 4 months post-treatment 4) Level of education, amount of sources of information and extrinsic religiosity were significant moderator variables	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Mishel, M.H et al.	2009	Managing uncertainty about treatment decision making in early stage prostate cancer: A RCT	RCT - longitudinal Some design issues	Acceptable practice	256 men with prostate cancer; 183 Caucasian and 79 Afro-American	This was a multiple psycho educational/communication intervention based on uncertainty management theory which included a video re talking to your Dr, a booklet on QA with a PQPL and 4 telephone calls from the nurse which concerned coaching: e.g. reviewing the materials and included help in identifying and rehearsing QA. Data was collected at 3 times-pre consultation/study entry, 4 weeks (post consult) and at 3 months (after treatment had commenced). Significant main effects were found for uncertainty management (increased cancer knowledge, problem solving, patient to provider communication) medical communication competence, an increased use of resources between entry and initial follow up. Intervention subjects rated the Dr as telling them more (p=0.04). There a lower rate of decisional regret following treatment. Supports the use of training interventions prior to consultations but the particular effects of the PQPL could not be isolated.	Combined intervention coaching & PQPL: Significant main effects for the intervention groups re 1) Cancer knowledge (p<0.01), problem solving (p<0.05), patient to provider communication (p<0.01) 2) Medical communication competence and use of resources 3) These effects were limited to first 4 weeks 4) Intervention subjects had a lower rate of decisional regret following intervention	USA
Roter, D. L.	1977	Patient participation in the patient-provider interaction	RCT -some design issues	Promising practice	200 adults with mixed problems, general practice - randomized	Combined intervention of coaching re QA and PQPL immediately prior to consultation, placebo group had a similar session on the use of health care facilities and there was another control group not randomly assigned. Intervention subjects took the PQPL into the following consultation. Audiotapes were analysed to identify the number, content and form of patient question asking behaviours. Intervention subjects asked more direct Qs and fewer indirect questions (in response to provider information) than the placebo group but the averages show this was a small effect e.g. mean of 2 Qs vs. 1 for direct Qs. The patient-provider interactions for the intervention group showed more signs of negative affect, anxiety and anger than the placebo group. The intervention group was less satisfied with their consultation but they demonstrated higher appointment keeping ratios over the following 4 months. No differences in consultation time. Author suggests the need for development and refinement of instruments for the study of patient-provider relationships and the need to assess this as a 2 way communication.	Combined intervention coaching and PQPL: 1) Intervention subjects asked more direct questions and fewer indirect questions (p<0.025) but the magnitude of differences were small 2) More negative signs in patient provider interactions for intervention subjects (p<0.05). 3) Intervention subjects had lower patient satisfaction than controls (p<0.05) 4) No significant difference in consultation time between the groups	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Roter, D.L	1984	Patient question-asking in physician-patient interaction	RCT -see above	Promising practice	62 intervention subjects and 61 controls	Same study as Roter 1977 but slightly less subjects used for this sub-analysis. Somewhat more detailed analysis of the correlates of question asking and patient satisfaction and notes the relationship between question asking variables and patient satisfaction differed for the experimental and placebo groups. Also noted more questions were identified by patients than were actually asked and the experimental subjects asked proportionally more questions by the content categories of diagnosis, prognosis and miscellaneous lifestyle issues	See above and note 1) Intervention subjects listed more questions than they asked and 2) They asked proportionately more question concerning diagnosis, prognosis and lifestyle issues	USA
Sander, R.W. et al.	1996	Patient-initiated prevention discussions: Two interventions to stimulate patients to initiate prevention discussions.	Linked study RCT. Study 1: Card 1 & Card 2 vs. Control. Study 2: Nurse intervention vs. control.	Acceptable practice (cards not reported separately)	Study 1 = 129 (87 = card intervention, 42 = control). Study 2 = 163 (104 = nurse intervention, 59 = control)	Study 1: Patients received one of two slightly different health concerns cards. Card 1 briefly outlined health concerns that patients may have and encouraged patients to tick their concerns and ask the doctor about them. The second card only included information about health concerns they may have. Controls did not receive a card. As there was little difference between the two cards, their results were analysed together and compared to controls. Study 2: Patients received a nurse intervention to help patients identify health concerns/ risk factors from a card and coaching on how to seek more information from the Physician. Patients either ticked off health concerns provided on the card and/or developed their own questions to ask the physician. Patients in both studies (intervention and control patients) filled out a baseline questionnaire, an exit questionnaire was then conducted after the intervention and a follow up interview was done 4-6 weeks after the intervention. Results from both studies suggest that more intensive methods are needed to help patients ask for information and be more involved in the consultation.	Combined intervention coaching and QPL. Study 1: Usability study. 1) Intervention patients (received either health care card) made significantly more health information requests than controls ($p = 0.03$). 2) No other significant effects observed re information recall or discussion of health promotion. Study 2: Combined intervention. The nurse facilitation intervention with PQPL increased requests for information ($p<0.001$) and recall of information ($p=0.0018$).	USA
Sepucha, K.R. et al.	2000	Building bridges between physicians and patients: results of a pilot study examining new tools for collaborative decision making in breast cancer	Pilot study, sequential controlled trial	Emerging practice	24 patients (12 control, 12 intervention)	This was a pilot study of a consultation quality improvement intervention for breast cancer patients. Both intervention and control/comparison groups received a pre-consultation visit to develop a patient agenda and to identify questions to be asked (PQPL). Intervention arm involved the researcher facilitating the pre-consultation discussion between the Dr and patient. The control group arm involved the researcher observing the Dr-patient pre-visit unless they were asked to participate. Intervention patients had higher final decision quality patient rating scores compared with control patients ($p = 0.008$) and a higher level of inter-subjective agreement with physicians about decision quality ($p < .0001$).There were no significant	Combined pre-visit consultation intervention including PQPL - with active facilitation and audio-taping or passive facilitation with observation recording of the consultation by the researcher. Outcomes concerned decision quality ratings. No significant differences in consultation time between groups.	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						differences in consultation time. The description of this study is quite unclear as is its main purpose. Authors felt that results of study support their hypothesis that active facilitation and recording improves the effectiveness of medical consultations.		
Sepucha, K.R. et al	2002	Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians	sequential controlled trial involving 2 centres	Emerging practice	Intervention = 42, control = 52	This study looked at two ways to prepare patients for a consultation, one more intense than the other. Intervention patients participated in a consultation planning session in which the patient filled out a questionnaire and a chart to link their questions and concerns and engaged in conversation about the upcoming consultation and their questions and concerns. A computer program was used to record and map the questions and concerns and print out a flow chart for the patient to take with them to the consultation. The patient was invited to role play the consultation and to develop an agenda. The control group listened to a productive listening session that included prompts by the researcher to reflect on their experiences re communicating with Physicians. Controls did not participate in any of the consultation planning exercises. Surveys of communication barriers and patient/physician satisfaction were also completed by both groups. The barrier of information overload was similar between the groups and the authors argued that providing more information to patients in information overload may not be the best way to help them.	Combined intervention - consultation planning & PQPL. Some question prompts and PQPL were included in consultation planning session but it was hard to tell what their effect was, especially as the comparison/control group also showed improved communication. Communication barriers were reported by 64% of patients. Both intervention and control groups reported significant reductions in communication barriers (p<0.001). Both intervention patients (p<0.001) and physicians (p<0.01) reported greater satisfaction with the consultation planning intervention.	USA
Sepucha, K.R. et al.	2003	Improving the quality of decision making in Breast Cancer: Consultation planning template and consultation recording template	Case study	Other: case studies	1 person	This paper describes the clinical application of the Consultation Planning Template and Consultation Recording Template through a case study in which each template was used with a specific patient. The CPT was administered before the consultation and the CRT was used during the consultation. CPT includes examples of prompts for the facilitators to present to the patient. A completed consultation plan includes questions the patient wants to ask. The CRT includes results of the consultation. Paper discusses the benefits and issues of the CPT and CRT.	This is a combined case-study intervention that includes consultation planning and recording. Development of PQPL is incorporated with other activities. Article outlines the concept of the interventions.	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Shields, C.G. et al.	2010	An intervention to improve communication between breast cancer survivors and their physician	RCT	Emerging practice	22 coaching participants and 22 care as usual participants	This study examined a communication coaching intervention with breast cancer survivors. Intervention participants received, 1 week prior to their appointment, a prompt sheet about their worries and concerns and telephone counselling with encouragement to talk to their physicians about worries and fears. As part of coaching participants were asked to limit what they wanted to raise with their physician to their top 3 concerns. These were then included in a summary sheet and mailed to the participant. Participants were encouraged to take the sheet with them to the appointment and talk to the physician about them. Control participants received care as usual. All participants were followed up 1 week and 2 months after their appointment. For intervention patients, 90% took the question sheet with them into the appointment and 80% rated it as useful. Authors reported some major categories for patient questions: symptoms, long term side effects, recurrence, cognitive changes, current treatment, help, and other cancer. Of the 54 questions intervention patients wrote, 16 contained positive emotions and 30 contained negative emotions, indicating that participants discussed their emotional concerns. Outcomes focussed on self efficacy.	1) The intervention significantly increased self efficacy at 2 months after appointment in relation to anxiety and satisfaction ($p<0.05$), depressive symptoms, health worries, womanhood worries, role worries and death worries ($p< 0.01$). 2) Change in self efficacy was a predictor of depression ($p <0.05$), anxiety ($p<0.0001$) womanhood worries ($p <0.05$) and marginally related to role worries ($p<0.10$). No direct analysis of communication behaviour or comparison of question asking behaviour in relation to controls	USA
Stacey, M. et al.	2012	Coaching older adults and carers to have their preferences heard (COACH): A RCT in an intermediate care setting .	RCT	Other - outline of study in progress	230 intermediate aged care patients	Outlines a study in progress that assesses the impact of a multi-component coaching intervention, including QPL, for elderly patients admitted to transition care with regard to choices for future care. Study includes both aged care patient and the primary care-giver. No data available as yet but it is unlikely that any of the effects of the use of the QPL could be disentangled from the effects of the multi-component intervention.	NA - in progress	Australia
Tabak, E.R.	1998	Encouraging patient question-asking: A clinical trial	RCT/pilot: post intervention measurement only	Emerging practice	35 intervention patients and 32 controls.	This study piloted an information/education booklet for patients to recognise and verbalise their information needs. Intervention patients received the information booklet, including a list of 33 commonly asked questions, while control patients also received a booklet that looked the same but was about clinic hours and services available. Patients were randomised to intervention or control immediately preceding their appointment. Audiotapes recorded the number of questions asked and a post-appointment questionnaire was used to assess patient satisfaction. Intervention patients asked more questions but it was not statistically significant. This may be because of the small sample size. A post hoc power calculation showed less	Combined intervention - education booklet including QPL. 1) Intervention patients asked 7.46 questions and controls asked 5.63 but the difference was not significant ($p = 0.14$) but that may be a Type 2 error. 2) Question asking did not correlate with the four satisfaction items ($p > 0.05$).	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						than 50% power to show a true effect. Question asking did not correlate with satisfaction in either controls or intervention patients.		
Tennstedt, S.L.	2000	Empowering older patients to communicate more effectively	RCT. Randomised at community site level. Post test only.	Emerging practice	36 Community sites; 355 patients - 155 intervention group and 200 controls.	Community-based trial of a patient activation intervention implemented 3 months before the patient visit to physician. Patients attended a two hour group program and were given written material that included a list of questions to ask the physician. Community sites were recruited (seniors centre or seniors housing) and were matched into pairs and then randomly assigned to the intervention group site or control site. Patients were recruited into the study at the site level (i.e. all patients received intervention group at intervention group site). Measures were self report taken at post-test only as it was thought pre-testing would influence patient behaviour. 54% of intervention subjects did not identify specific issues, 77% did nothing to prepare for visit, and over 80% did not have a list of questions or ask questions. Less than one third asked questions or stated preferences although 76% were satisfied with the medical visit. There was a non-significant trend for people in the intervention group to bring a list of questions; and intervention group participants were more likely to be satisfied. When those who missed the intervention (they were sick on the day etc.) were excluded there was a significant trend for those who attended the program to engage in more active behaviours at the physician visit, although it was not stated what those behaviours were. Given that there was up to 3 months between intervention and the physician visit, many patients may have forgotten what they did in the intervention.	Combined intervention, patient activation and QPL. 1) There was a non-significant trend for intervention group patients to report target behaviours and bring a list of problems and questions to the Dr visit ($p<0.08$). 2) Intervention group participants were more likely to be satisfied with the visit ($p<0.05$). 3) Program attendance was associated with a greater number of self-reported active behaviours during the physician visit ($p<0.05$). 4) Active behaviours were also associated with younger age ($p<0.001$) and female gender ($p<0.01$) Limitation: 3 months between intervention and physician visit.	USA
Van Weert, J. C. et al.	2011	Effects of communication skills training and a Question Prompt Sheet to improve communication with older cancer patients: a RCT.	RCT -pre and post-test control group	Emerging practice as design elements are quite unclear	Pre-test, 64 Intervention, 51 controls: Post-test 55 intervention, 40 controls	Following a pre-test consultation (baseline) Oncology Nurses in the intervention condition received communications skills training with video-feedback which also included instruction re using a QPL with patients. Control nurses only received education as usual. Intervention patients also received QPL during a pre-visit education consultation with nurse prior to the chemotherapy consultation. Controls did not receive the QPL and had a usual practice consultation. The QPL significantly increased question asking compared to controls. The differences re overall knowledge recall at post-test were only marginally significant for Intervention subjects compared to their pre-test and only occurred in 2 areas (re hygiene and side-effects). Hard to disentangle effects of nurse communication	Combined intervention, nurse education and QPL:1) Intervention subjects asked more questions overall compared with controls ($p<0.05$) and 2) about treatment related topics ($p<0.05$) 3) Marginally significant change in overall knowledge recall for Intervention subjects from pre-treatment to post treatment mainly concerning the areas of	Netherlands

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						skills intervention from patient QPL intervention. Notes limits of short-term memory (e.g. 7 items) may place a ceiling on the amount of knowledge that can be recalled from consultations.	hygiene (p<0.05) and side-effects (p<0.05)	
Walker M.S. et al.	2005	Video preparation for breast cancer treatment planning: results of a randomised clinical trial	RCT	Acceptable practice	42 patients received video, 37 received pamphlet.	Patients were identified from a Breast Health Centre and recruited 1-3 days before their clinic visit. They were randomly assigned to either a video intervention or a pamphlet intervention. Patients agreeing to participate were asked to arrive 1hr before their appointment to collect baseline information and receive the intervention. Those in the video group watched a 19 minute video to prepare for their visit and received advice on how to make the most of the appointment and basic questions to ask their doctor. The pamphlet group received a 2 page pamphlet with a written summary / description based on the video and did not receive a list of suggested questions to ask. A follow-up questionnaire was mailed to participants a week after the appointment. Regarding the QPL - it's not reported what questions were provided to patients. The authors stated that the beneficial effects of the intervention were felt more by those patients with greater psychosocial need.	Combined intervention training video and PQPL: 1) Those patients in a minority group who received the video were more satisfied with the appointment than minority patients who received the pamphlet (p=0.042). 2) Patients who watched the video reported being more prepared for their appointment (p=0.050) and felt more prepared to ask questions (p=0.05).	USA
Wetzels, R. et al.	2005	A consultation leaflet to improve an older patient's involvement in general practice care: a randomized trial.	Cluster RCT – design issues	Emerging practice	25 general practices and 318 patients > 70	Evaluated the effects of a programme to enhance the involvement of older patients in GP consultations. Patients in the intervention group received a leaflet to help them prepare for the consultation. All patients aged 70 or over in the intervention group received a consultation leaflet by mail (unclear re time interval before the next consultation). The leaflet consisted of a short motivating text on patient involvement and a mixture of open and pre-structured questions to help patients prepare for the consultation and to prioritize which problems they wanted to discuss with their GP. GPs received an outreach visit to optimize older patient's involvement when visiting their GP. Patients in the control group received usual care. No differences in effect as a result of the leaflet on involvement, enablement or satisfaction were found between the intervention and the control group. Of 318 patients who received the leaflet & visited their GP in the intervention period, 47 (15%) patients used the leaflet.. Users reported more psychological problems than non-users. Given the low usage rates by intervention subjects face-to-face presentation of the intervention may have been more appropriate, immediately before the consultation.	Combined related intervention: GP training and leaflet with some topics/questions included but it is not clear what the patient should do with them. 1) Intervention group leaflet users reported more psychological symptoms to their GP compared with non-users of the leaflet (p= 0.034). 2) No other differences were found. Roughly one third of non leaflet users (25 of 74) and almost two third of leaflet users (28 of 47) said they prepared for consultations (p= 0.003). Not really a QPL or PQPL and the intervention usage rates are so low this study has not been included in the summary table.	Netherlands

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Wilkinson C. et al.	2002	Strengthening patient-provider relationships	RCT	Emerging practice	277 veterans, primary care, randomised	Veterans attending primary care team visit were randomised to receive usual care or an intervention which included a guidebook concerning consultation preparation, including a space to write down their questions (PQPL), and an appointment reminder letter. However, the intervention guidebook appeared to focus more on keeping appointments rather than question asking during the consultation and the study did not examine outcomes related to question asking or participation in the consultation. The controls received only the appointment reminder letter. No significant differences found re agreement with statement concerning primary care visit effectiveness although ceiling effects were noted. Did detect significant differences in the proportion of intervention patients vs. controls who received preventive vaccinations and gender specific cancer screening.	Did not examine any key outcome variables related to question asking. Unclear about the degree of focus on question asking. Not included in summary table	USA

Table 5 Studies Concerning PQPL/QPL Acceptability, Usability and Development

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
Acceptability, Usability, Development								
Albada, A. et al.	2011	Use and evaluation of an individually tailored website for counselees prior to breast cancer genetic counselling.	Monitoring web site use	Emerging practice	101 counselees	Usability testing of a tailored, hospital pre-visit website for those requesting breast cancer genetic counselling. Included blank PQPL sheet. 42% patients formulated 1 question and the average was 3 questions. Users of PQPL more highly educated. PQPL use greater for those viewing the web page concerning consultation with the counsellor on the website.	1) Relatively low rates of a PQPL (42%) use on website where use is optional 2) Users of PQPL more highly educated (p=0.03)	Netherlands
Anderson, H. et al.	2001	Evaluation of the Chemotherapy Patient Monitor: an interactive tool for facilitating communication between patients and oncologists during the cancer consultation.	Pilot testing of QPL style tool	Emerging practice	Initial study 24; audit study 34	The Chemotherapy Patient Monitor is really a checklist including a PQPL of side effects and concerns re chemotherapy for advanced colorectal cancer patients. The initial consultation was a baseline consult and the CPM was used in 2 subsequent consultations - the patient completed it immediately prior to these consultations and it was endorsed by the clinician. All patients understood the CPM and 92% felt it improved visits, 83% oncologists found it useful and consult time was not increased for 82% of visits.	1. Positive feedback re patient acceptability (92%) of Dr endorsed CPM which included PQPL component 2) All patients understood the CPM 3) 83% oncologists found it useful	UK
Belkora, J. K. et al.	2008	Training communication resource center	Follow-up implementation rates	Routine practice	18 trainee interviews	Consultation planning is a visit preparation technique where a trained coach elicits and documents patient questions (PQPL) prior to a consultation. Provided training for 32 trainees in consultation planning at a medical clinic and at a resource centre. 18/32 trainees were interviewed and 14/18 had implemented CP but there was the potential for selection bias. Most of the resource centre trainees had implemented CP whereas most of the medical clinic trainees had not. Resource centres with a clinical champion had higher rates of implementation and the major barriers to implementation identified were resource constraints and conflicting priorities.	Considers implementation aspects of using PQPL within consultation planning. Clinical champions can facilitate implementation. Barriers identified were resource constraints and conflicting priorities	USA
Belkora, J. K. et al.	2009	Implementing decision and communication aids to facilitate patient-centered care in breast cancer: A case study.	Case study	Case-study	1 patient	A patient provided feedback concerning decision support interventions experienced. She used a decision aid to educate her husband about her care; found the QPL aided her consultation, found the audiotape useful in enhancing her recall re need for genetic counselling and reviewed the consultation summary at 30 days to reflect on her decisions. She experienced a reduction in decisional	A case-study on usefulness of QPL use in a consultation - anecdotal	USA

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
						conflict and reported increased knowledge. The QPL intervention was associated with a small decrease in self efficacy. Authors suggest decision support interventions can be used to enhance patient centred care and could be used more routinely for breast cancer patients.		
Brown, R. F. et al.	2012	Testing the utility of a cancer clinical trial specific Question Prompt List (QPL-CT) during oncology consultations.	Pilot testing of QPL-CT	Emerging practice	30 patients from 6 oncologists	Tested feasibility and patient feedback concerning the use of a 33 item QPL prior to a consultation for patients concerning whether to participate in a clinical trial. All questions were wanted to be asked by at least 1/3 of patients but only 17 Qs were wanted to be asked by 60% of patients. Subjects mainly wanted and asked Qs about personal benefits from trials. The paper is one of the few that reports data on type of questions subjects wanted to ask and did/did not ask e.g. whether the treatment showed promise, costs/ benefits of treatment, conflict of interest issues etc. As the patients did not ask some questions they wished to ask they were left with unanswered questions. Authors suggest that a QPL that is endorsed and addressed by the clinician may help to address such issues. Further research may identify predictors of asking Qs about difficult or sensitive areas.	Largely descriptive analysis /feasibility testing of QPL-CT. Reports on questions patients did ask, wanted to ask and did/did not ask. Only 17/33 questions on the QPL were asked by 60% of patients. An interesting feature was the type of questions 60% of patient wished to ask (15 Qs) but were rarely asked e.g. whether the treatment showed promise, costs/ benefits, conflict of interest issues etc.	USA
Brown, R. F et al.	2013	Perceptions of participation in a Phase I, II, or III Clinical Trial among African American patients with cancer: What do refusers say?"	Patient interview and questionnaire	Emerging practice	22 African Americans	Article re factors influencing patient involvement in clinical trials. Special needs groups such as African Americans are less likely to agree to participate due barriers such as fears of additional burden and adverse effects. Misunderstanding by both patients and families of the clinical trials and family influence to not participate were also factors. The majority of participants (91%) had high needs for information and wanted to share decisions (68%). Most participants (64%) felt that being provided with a question prompt list before their discussion about the clinical trial may have been helpful.	Examined factors which influence African Americans to participate in cancer trials. QPL usability issues; the use of a QPL re clinical trials may be useful to facilitate questions about clinical trial participation amongst ethnic groups	USA
Brown, R. F. et al.	2011	Identifying patient information needs about cancer clinical trials using a Question Prompt List.	Focus groups of patients; clinician feedback	Emerging practice	11 trial naïve patients and 9 trial experienced cancer patients;	Usability of a QPL re clinical trials. Patients varied with regard to their information needs within both groups. Overall trial experienced patients wanted to input their patient preferences more whereas naïve subjects wanted general foundational knowledge. All patients viewed the 33 Question QPL positively and felt that is would help them to ask difficult questions. Clinicians had mixed feelings about the QPL feeling it may overburden patients with the potential of too much information to consider.	QPL-CT usability feedback 1) All patients viewed the QPL-CT positively (N = 20) 2) clinicians had mixed feelings feeling it may overburden patients with too much information to consider	USA

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
Brown, R. F. et al.	2011	Enhancing decision making about participation in cancer clinical trials: development of a question prompt list.	Focus groups of patients	Emerging practice	11 trial naïve patients and 9 trial experienced cancer patients;	Same study as above. A qualitative analysis of focus group data concerning decision making themes, particularly perceived risks and benefits of the trial and degree of trust in the Drs recommendations. Trial experiences subjects viewed trial participation more favourably whereas naive subjects focussed more on risk. The level of trust in the Drs recommendations influenced decisions re trial participation. Disease severity only influenced trial decision making for naive subjects. Although all subjects preferred a paternalistic decision making style they thought the QPL-CT could aid decision making and be useful more broadly as preparation for the consultation and as an education aid.	QPL usability feedback (see study above):1) although most subjects preferred a paternalistic decision making style they thought the QPL-CT could aid decision making and be useful before, after and during consultation	USA
Caminiti, C. et al.	2010	Cross-cultural adaptation and patients' judgments of a question prompt list for Italian-speaking cancer patients.	Other: Linguistic validation	Acceptable practice	30 cancer patients	Italian language validation of existing Australian QPL for cancer patients. Used backward and forward translations.	Translation QPL	Italy
Clayton, J. et al	2003	Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients.	Qualitative methods, pilot testing	Emerging practice	19 patients, 24 carers, 22 professionals. Pilot test 23 patients	Development of a QPL to be used prior to palliative care consultation for advanced cancer patients. Most patients considered the QPL useful and thought end of life issues should be included. At 112 questions this is a very long QPL. A more detailed analysis of items actually asked by the pilot study patients and caregivers in the following consultation may have suggested ways to shorten it.	QPL usability palliative care 1) Most patients considered the QPL useful 2) They wanted end of life issues included. At 112 Qs this is a very long QPL	Australia
Cunningham C. et al.	2000	A question sheet to encourage written consultation questions	Trial of PQPL with comparison group	Emerging practice	162 patients attending two paediatric neurology clinics	Parents at a paediatric neurology clinic were offered a question sheet which asked them to identify their Qs prior to the consultation and to take it into the consultation. 41% of subjects declined the question sheet and 47% of subjects used the sheet in the consultation. Of these subjects sixty four (88%) liked the PQPL sheet, seven subjects (9%) rated it as neutral and two (3%) disliked it. Interviews with 3 trainee Drs indicated they felt more satisfied with the consultation and there was no evidence of increased demands, although there may be some increase in consultation duration. The main benefit identified by doctors was that with written questions unpredictable issues emerged along with things which the doctors thought had been dealt with previously. Doctors became aware just how often they assumed explanations had been understood, when clearly they had not. Consultation length appeared to increase initially with the use of PQPLs,	Usability of PQPL 1) patient uptake rates of 47% 2) 88% of users liked the PQPL sheet	UK

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
						however, as patients who had used the PQPL returned for further visits consultations were shorter and more focussed.		
Danesh, M., J. et al.	2014	Informational needs of patients with metastatic breast cancer: what questions do they ask, and are physicians answering them?	Qualitative analysis of patient question lists & Dr responses	Acceptable practice	59 metastatic breast cancer patients	Examined patient developed question lists and the resulting consultation summaries. Patients most often asked about prognosis (64%), symptom management (53%) clinical trials (73%)and quality of life (64%) whereas Drs answered questions about prognosis rarely (37%) and focussed more on symptom management, clinical trials and quality of life. Question lists (PQPLs) may be insufficient to bridge the gap between patient information needs and doctor's focus; training may be required to address information gaps such as prognosis	Noted that 64% patient questions/ PQPLs concern prognosis and although these Qs were asked Drs rarely addressed (37%) these questions in the actual audio-taped consultations	USA
Dimoska, A. et al.	2012	Implementing patient question-prompt lists into routine cancer care.	Patient surveys re use of QPL	Routine practice	389 QPL patients, 139 patients surveyed post consultation, 10 specialists surveyed	Four cancer centres in NSW distributed QPLs to 389/606 patients (64%). Of Patients offered a QPL 91% accepted; and of 139 patients surveyed post consultation 89% read it and 44% used it in the consultation. All 10 cancer specialists surveyed indicated that QPL implementation was feasible and did not strain resources. Authors identify strategies to enhance implementation in routine practice.	If optional for patients QPL acceptance rates were 91% to be sent it but only 44% reported using it in the consultation	Australia
Eggly, S. et al.	2013	Development of a question prompt list as a communication intervention to reduce racial disparities in cancer treatment.	Qualitative research-semi-structured interviews, pilot testing	Emerging practice	19 patient interviews	Given racial disparities in cancer chemotherapy treatment a QPL was developed by a number of research partners to improve communication and treatment for consultations where oncologists and Black/African American patients discuss chemotherapy. Patients also identified themes and a number of barriers to communication. The QPL was pilot-tested with 19 Black/ African American patients the majority of whom were females with breast cancer and had/ or were receiving chemotherapy. The final QPL had 43 questions across 7 areas and was generally endorsed by patients and research partners as a communication tool. Further research is being undertaken to assess whether it improves communication and influences treatment options and outcomes for African American cancer patients.	QPL pilot testing - ethnic groups	USA

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
Flessig, A. et al.	1999	Encouraging out-patients to make the most of their first hospital appointment…..	RCT but design/data issues	Emerging practice	Unclear but 1077 patients including controls returned survey, 369 Help Card Intervention	Intervention outpatients received a Help Card (similar to QPL) 2 weeks prior to consultation which suggested 23 questions to ask in the later outpatient hospital consultation. Half the patients who received the Help Card reported it enhanced the consultation but no other differences between the intervention and control groups were found re question asking but it is unclear what analyses were undertaken. The study design is quite unclear, and only a post follow-up survey was used which also asked subjects to report on issues prior to the intervention and may have been affected by the consultation. The long period between receiving the Help Card and the consultation may have affected results. Not conclusive.	Descriptive and suggestive analysis of usability - 50% of patients report QPL enhanced the consultation	UK
Fleisher, L et al.	2008	Using health communication best practices to develop a web-based provider-patient communication aid.	Pilot -testing of web pre-visit intervention	Emerging practice	6 patients usability testing	A web based communication aid - CONNECT - which included questions to ask the Dr (QPL) - was tested for usability and 70% found the module helpful and 50% found it affected the consultation. Numbers too small to be conclusive.	Descriptive usability information re web-based communication aid/QPL; small sample	USA
Frederickson , L. et al.	1995	Evaluation of a patient education leaflet designed to improve communication in medical consultations.	RCT -design issues	Emerging practice	80 patients of a single doctor; leaflet = 40, control = 40.	Oncology patients were provided with an education leaflet in the waiting room outlining what to tell the doctor and to ask for more information where required. The doctor rated patient communication as poor, average or good. The doctor rated 57% of control group consultations as good and 80% of leaflet group consultations as good. Patients also responded positively to the leaflet. Small sample and use of single doctor limits generalisability.	Related to QPL implementation re Dr endorsement and Dr satisfaction	UK
Glynne-Jones, R. et al.	2006	Can I look at my list? An evaluation of a 'prompt sheet' within an oncology outpatient clinic.	Clinical audit re QPL -satisfaction survey	Routine practice	300 clinic patients-mixed cancers	A QPL was introduced in a cancer outpatient clinic over a 1 year period. The follow-up survey examined clinic satisfaction, patient information needs and patient satisfaction concerning the use of the QPL. Only 254/300 (85%) patients remembered receiving the QPL and overall 65% of patients found them very helpful; 10% found them fairly helpful; 5% had no strong feelings, 1% found them unhelpful and 15% did not recall them and some patients did not complete these questions (4%). The authors state that 1/3 of patients reported asking more questions as a result of the QPL. Patients with prostate cancer reported finding the QPL particularly helpful.	Survey usability data 1) 65% found QPL helpful 2) 33% of patients reported asking more Qs due to QPL	UK

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
Goss, C. et al.	2013	Involvement breast cancer patients during oncological consultations. INCA.	RCT outline - proposal only	Other -study outline	Proposed to recruit 130 intervention subjects and 130 controls	Proposed testing of a translated 50 item QPL for Italian speaking cancer patients - prior to initial oncology consultation. Control and intervention subjects, pre and post data, audio-taping and analysis. Consultation includes caregiver where available and carer data will also be collected. A query concerning how they will differentiate effects of intervention by patient and caregiver. A rather large battery of other psychological (6) tests to be completed by all patients pre and post treatment.	QPL usability - translation	Italy
Hartmann C.W. et al.	2007	A website to improve asthma care by suggesting patient questions.	Usability testing of an asthma website	Routine practice - usability testing	37 asthma patients, 26 physicians	The study investigated the impact and the experience and using an interactive patient website designed to provide patients with individual feedback about their condition and to suggest tailored Qs for patients to ask their physician. Outcomes were feedback about the usability of the website by patients and physicians - no actual consultation occurred following the website activity. Generally the feedback from patients and physicians was positive but its impact on consultations remains to be assessed.	Reports computer generated PQPL acceptability only	USA
Hebert, R. et al.	2009	Pilot testing of a question prompt sheet to encourage family caregivers of cancer patients and physicians to discuss end-of-life issues.	Development and pilot testing of QPL	Emerging practice	Development: 33 caregivers, 23 patients, 15 health providers; Pilot testing - 50 caregivers	A QPL for family caregivers of patients with advanced cancer was developed with input from caregivers (33) patients (23) and health care providers (15). It was pilot tested with 50 family caregivers who received it immediately prior to their consultation and who ticked questions they wished to ask. The QPL was provided to the clinician. A post -consultation survey of caregivers indicated high levels of satisfaction with the QPL. They felt it was easy to understand, easy to complete and 85% thought they had enough time to ask their questions and 75% felt it made it easier to ask questions. Further empirical testing is required.	Development of QPL. Reports on Caregiver QPL acceptability - 75% of caregivers thought the QPL made it easier to ask Qs	USA
Jones, R. et al.	2002	Does writing a list help cancer patients ask relevant Qs.	retrospective doctor survey	Emerging practice	Dr feedback re 478 radiotherapy patients, 438 patients interviewed	Opportunistic use of subjects recruited to another trial. 478 subjects were asked to write a list of questions they wished to ask their doctor and to take it with them to the next consultation in 3 weeks time. It is unclear whether this was an initial consultation or occurred during the process of treatment. Drs received a questionnaire about each patient concerning the use of the patient question sheet. According to doctors only 46% of patients took their question sheet to the consultation. Of 438 patients interviewed 58% indicated they used their QPL. Drs thought that 34% of patients would not otherwise have asked the Qs they identified and	Usability of PQPL - 58% patients indicated they used the PQPL but Dr's reported only 46% of patients used it.	UK

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
						they thought that 91% of the prompted discussions were worthwhile. An opportunistic and poorly controlled study.		
Langbecker, D. et al.	2012	Development and piloting of a brain tumour-specific question prompt list.	Pre-post pilot study with small control group, no randomisation	Emerging practice	10 intervention; 10 controls	Non-randomised pre-post pilot study of acceptability of QPL with 20 brain tumour patients. All patients received an information booklet, 10 patients also received a QPL booklet- but some did not read this as it was 33 pages long and the number of questions is not clearly identified. Of the seven patients that used the QPL all thought it contained useful questions. The timing of the consultation interviews is mixed over the period of treatment and feedback indicated that patient's felt it more appropriate to use the QPL at the beginning of treatment.	Usability feedback re QPL	Australia
McJannett, M. et al.	2003	Asking questions can help: development of a question prompt list for cancer patients seeing a surgeon.	Outline of the development of a QPL for cancer surgery	Emerging practice	Four focus groups - 22 post-surgical patients; 1 focus group of 9 allied health professionals	Development of a QPL for cancer surgery. A QPL with 59 questions across 5 theme areas was derived. Patients with metastatic disease were not included in the focus groups. QPL yet to be tested in empirical studies. Methods for theme analysis were not clearly described.	Development of QPL: cancer surgery	Australia
Martinali J. et al.	2001	A checklist to improve patient education in a cardiology outpatient setting	RCT - -some design issues	Acceptable practice	53 Intervention subjects; 50 controls	Intervention cardiology outpatient subjects received a 49 item QPL and a CAD information brochure 1 week prior to the consultation whereas controls received just the brochure. The consultation was mid way during the course of treatment. State anxiety immediately before the visit was lower for intervention subjects (p=0.02) and there were no differences in patient satisfaction or the length of consultation between the groups. Only 75% of intervention subjects completed their checklists prior to the intervention. Of those that did 47% indicated that it had not resulted in greater exchange of information although 38% thought it had. 71% of intervention subjects thought they would use it again for their next visit.	QPL usability rates 1) only 75% of intervention subjects completed the checklist 2) of these subjects 38% found it useful and 38% did not 3) 71% of users thought they would use it again.	Netherlands
Pass, M. et al.	2012	Physician behaviours surrounding the implementation of decision and communication AIDS in a breast cancer clinic: a qualitative analysis of staff intern perceptions.	Qualitative analysis of program records	Routine practice	126 intern reflections	Communication aids and decision aids were implemented in a breast cancer clinic and the study concerns the factors that enhanced of impeded their use. Implementation of aids involved the use of interns to show a video decision aid, elicit patient questions, and forwarding the Qs to the Dr prior to the intervention, audio-taping the consultation and identifying unasked questions during the consultation.	Implementation issues - communication aids including PQPL. Intern reflections indicated benefits when the consultant had read through the patient's PQPL in advance	USA

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
						Facilitators included bringing the PQPL to the consultation and including the staff interns in the consultation. Barriers included were forgetting to bring the intern to the consultation or discouraging them from speaking during the consultation. Interns noted benefits when the consultant had read through the patient questions in advance.		
Posma, E. R. et al.	2009	Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals.	Qualitative - focus groups patients and carers (2) health professionals (3)	Emerging practice	38 patients & carers in focus groups, 5 patient interviews; professional focus groups 20	Concerns older persons information needs prior to chemotherapy for cancer. Suggests older patients may require more individually tailored, but concrete and structured information; and an empathic environment to allow exploration of patient issues. Aids to enhance question asking and recall of information could also be explored. Study might suggest the need for a short QPL for older patients receiving chemotherapy.	Implementation issues - suggests need for aids for QA and Knowledge recall for older patients.	Netherlands
Shirai, Y. et al.	2012	Patients' perception of the usefulness of a question prompt sheet for advanced cancer patients when deciding the initial treatment: a randomized, controlled trial.	RCT	Promising practice	32 intervention; 31 controls	Intervention subjects received 53 item QPL and hospital information sheet (HIS) and controls received HIS only - randomised allocation. No difference in total question asking, or by content area, between the groups. The intervention subjects rated the QPL material as more useful for asking questions, more useful for understanding the treatment plan and they were more willing to use QPL materials in future than were the controls.	QPL intervention subjects 1) Rated the QPL material as more useful for asking Qs (p=0.033) 2) More useful for understanding the treatment plan (p=0.051) and 3) Were more willing to use these QPL materials in the future (p=0.006) than controls	Japan
Tai-Seale, M. et al.	2013	Patients with mental health needs are engaged in asking questions, but physician's responses vary	mixed methods analysis of audio recordings	Emerging practice	322 audio recordings of mental health patient / doctor discussions	This study investigated whether findings regarding the benefits of patient question asking can, mostly from studies in cancer care and geriatrics can be applied to mental health patients in a primary care setting. Findings supported that patients who have mental health problems, despite the nature of the illness, were no different to a broader patient population in regards to question asking. A potential bias of the study was that it included only older and insured patients, which limits generalisability. Patients were also not 'new' so were in an existing relationship with their doctor. Findings included that if patients brought a list of questions that this increased the length of the discussion by 3.2 minutes. Patients who asked more questions rated their physician's relational communication as poorer particularly regarding openness and composure. Patients asked more questions about topics that occurred more frequently in conversation, possibly indicating that patients used questions as a way of re-directing the conversation	The study results indicated that where patients brought a list of questions to the consultation (very few) there was an increase in length of visit ($p < 0.01$). Patients that asked more questions rated the physicians' relation communication as poorer. Female and better educated patients asked more questions	USA

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
						back to topics they felt were unresolved.		
Volz, S. et al.	2013	Do patients use decision and communication aids as prompted when meeting with breast cancer specialists?	Follow-up survey of use of aids following prompting	Routine practice	195 patients	Communication aids and decision aids were routinely provided to new patients in a breast cancer clinic and 195 patients were prompted to use them. Patients were surveyed following the consultation but only 42% responded. Of these nearly all reported viewing some or all of the booklets (92%) and 71% viewed some or all of the DVDs. 81% reported they wrote a question list but only 23% showed it to their Dr. More patients reported following prompts to use decision aids vs. communication aids. Exploratory analyses indicated associations between using communication aids and race/ethnicity and level of education which require further investigation	PQPL usability issues 81% of prompted patients reported they wrote a PQPL but only 23% of these patients showed it to their doctor. Race and ethnicity issue require further investigation.	USA
Walczak, A. et al.	2013	A question prompt list for patients with advanced cancer in the final year of life: Development and cross-cultural evaluation.	Thematic analysis of transcripts from semi structured interviews and focus groups	Emerging practice	34 patients with advanced cancer (in Aust and USA) and 13 health professionals	The study of the use of QPL for end of life care for oncology patients found that patients and health professionals endorsed the question prompt list as acceptable and useful. Patients illustrated how QPLs could ameliorate information overload commonly experienced when first informed they had incurable cancer or transitioning from curative to palliative treatment. Many wished that they had received the QPL early in their disease trajectory at one of these critical moments. Several suggested that 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. Feedback resulted in two distinct versions of the question prompt list, accommodating differences between Australian and US approaches to end-of-life discussions, highlighting the appropriateness of tailoring communication aides to individual populations.	Usefulness of QPL for end of life care for oncology patients. Some patients found a QPL useful to address information overload at critical points in their care. Two versions developed to accommodate differences between US and Australian approaches to end-of-life discussions. Highlights the appropriateness of tailoring communication aids to individual populations.	Australia / US
Wells, T. et al.	2004	The patient's written word: a simple communication aid.	Qualitative and quantitative analysis of data	Acceptable practice	88 oncology outpatient participants	This study on PQPL suggested that limitations of QPL are that listing questions for patients to tick is patronising and paternalistic and it might even influence their agendas. Patients were given a template on which to write the questions they would like to ask their doctor. Of the 88 participants, 65 listed one or more questions/topics. The study found that the number of questions listed was not related to prognosis, gender, age, marital status or deprivation scores of the patients. Patients in the early	Examined use of a PQPL by patient use, topics included, and patient characteristics associated with the use of the QPL	UK

First Author	Year	Topic	Study Design	Strength of Evidence	Study Nos.	Summary	Significance of Effect	Country
						stages following cancer diagnosis were more likely to have more questions. However a limitation of the study is that patients may have been influenced to list questions by being given the template sheet and it is unknown how many would have asked the questions anyway. Doctors' communication skills are of paramount importance, whatever interventions are used to improve clinic consultation dynamics.		
Wen, K-Y. et al.	2012	The development and preliminary testing of a multi-media patient-provider survivorship communication module for breast cancer survivors	Iterative developmental process including content development, user testing, usability testing.	Routine practice	Usability testing 10, preliminary web usage data 256	The survivorship communication training module was developed and enhanced using feedback from the target audience during a systematic iterative developmental process. Participants' preliminary usage provides support for the potential of the multimedia communication training intervention for breast cancer patients who are completing their active medical treatments and transitioning into survivorship. The most frequently accessed component across users was the survivorship care plan (71.7%), followed by the adjuvant treatment summary (67.8%), interactive question prompt list (64.5%), health care team roles (61.2%), text-based educational materials (48.7%), and role modelling video (25.7%). The finding that the interactive question prompt list was frequently accessed among this highly educated cohort of survivors highlights survivors' need to frame questions for discussion with their health care providers.	In a multi-media web-site intervention The online training module included an interactive question prompt list and it was found that 64.5%of intervention subjects accessed this component.	USA

Table 6 Literature Overview: Reviews and Summary Articles Concerning Question Lists

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Dimoska, A. et al.	2008	Can a 'prompt list' empower cancer patients to ask relevant questions	Literature Review	Acceptable practice	QPL in cancer care	Fifteen studies identified included 9 RCTs, 2 sequential time controlled studies and 4 uncontrolled or observational studies. The QPL did not increase the total number of questions asked, but in all RCT studies more questions were asked about prognosis and no adverse psychological effects (e.g. anxiety) were reported. Raises the important issue that the optimal length of a QPL is yet to be determined as the QPLs ranged from 10-112 questions. Notes lack of studies with using QPLs with cancer patients from non-English language background. Recommends physician endorsement of QPLs and identifies a range of areas for future research.	Review conclusions: 1) QPL did not increase total QA, 2) there were more Qs concerning prognosis and 3) no adverse effects reported	Australia
Friedrichsen, M.	2008	Does a prompt list help patients and caregivers to ask questions about cancer prognosis and care	Brief opinion piece	Expert opinion	NA	Briefly summarises recent studies e.g. Clayton et al. (2007) which indicate that a QPL increases patient question asking particularly with respect to prognosis. Raises the important issue of whether an increased number of Qs by patients is a sign of quality or quantity. Suggests the QPL could be applied in palliative care but suggests the shortening of the QPL. Notes we still do not fully know how patients interpret and recall information or whether a QPL will help patients from different cultures.	Brief literature summary (2008) 1) QPL increases patient question asking particularly with respect to prognosis. 2) Raises issues of length re QPL 3) raises cultural issues re use of QPL	Sweden
Gaston, C. M. et al.	2005	Information giving and decision-making in patients with advanced cancer: a systematic review.	Systematic Literature review	Acceptable practice	47 SDM and information provision papers re advanced cancer; 22 papers re early cancer	Systematic review (2005) on information giving and decision making in patients with advanced cancer. Almost all patients wanted full information but only 66% wished to participate in active decision making. Higher education, younger age and female gender were associated with the desire to participate in active decision making. Literature examined concerning the use of QPLs to encourage participation (6 papers) indicated that QPLs are more useful when endorsed and referred to by the doctor. A QPL was found more useful than a patient information sheet and patients using QPLs identified prognosis as an important area for inclusion in the consultation. Dr's fears that QPLs might increase patient anxiety or prolong consultations were not evidenced by the studies and there was some limited evidence (1 study) that the QPL can make the interview more efficient. Note searches identified substantially less early literature than the Kinnersley et al. (2007) review.	Review (2005) on information giving and decision making for patients with advanced cancer. Notes for QPL 1) Increase in prognosis Qs 2) QPL more effective with Dr endorsement and Dr use 3) no consistent evidence re QPL use prolonging consultation 4) No increase in patient anxiety	UK

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Harrington, J et al.	2002	Improving patients' communication with doctors: a systematic review of intervention studies	Systematic literature review	Promising practice	25 studies	Identified 25 papers describing 20 studies designed to increase patient participation in consultations - these could include written intervention such as brochures, leaflets and QPL or PQPL or interventions such as coaching and modelling or combinations of these types. The paper does not analyse QPL/PQPL studies as a group. Fourteen studies appeared to use QPL/PQPL/list of patient concerns but some studies combined QPL with other methods. In the majority of papers question asking was assessed but only in 2/10 written interventions was there a significant increase in question asking. For those that used a QPL/PQPL alone one study found a significant increase in QA and 4 no increase; 2 combined interventions with QPL reported a significant increase in question asking. Most studies up to this time only examined total question asking and did not examine differences in question asking by area (e.g. prognosis). The author notes that studies which examined patient requests for clarification following a Dr's remark, rather than the total number of spontaneous questions asked more often found significant differences in patient participation but it is quite unclear from the review how a request for clarification is operationally differentiated from question asking.	Review article (2002) concerning interventions to increase patient participation. Overall half of the various patient participation interventions improved participation either through question asking or patient clarification request behaviours. Notes that only 2/10 written interventions increased total question asking. Variable findings re patient satisfaction. Does not analyse findings for QPL/PQPL papers as a group. Notes methodological issues for many studies.	UK
Henselmans, I. et al.	2013	Enhancing patient participation in oncology consultations: a best evidence synthesis of patient-targeted interventions.	Systematic Literature review	Promising practice	Literature review - 5 QPL studies	A broader review of patient targeted interventions to enhance cancer patient's participation in the consultation. 5 QPL interventions were reported in 12 publications. Evidence reports increases in the number of questions of a specific type (e.g. prognosis) rather than on total question asking and QPL interventions focus only on question asking rather than broader patient communication behaviours. Effects of the interventions could only be observed for intermediate outcomes (consultation behaviour) rather than longer term outcomes including physical and psychological well being or other factors such as patient satisfaction and consultation duration.	Review 2013 re enhancing patient participation, oncology; QPL studies 1) no increase in overall question asking, 2) more Qs re prognosis 3) no effect on patient satisfaction or 4) consultation length	Netherlands

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Kinnersley, P. et al.	2007	Interventions before consultations for helping patients address their information needs (Review)	Systematic literature review using meta-analytic methods	Supported practice	33 RCT studies	Meta-analytic review of pre-consult interventions to foster question asking but these could include QPL (14 studies); Coaching (11 studies) Other written materials (8 studies) and these studies were combined for the analyses. Overall small but significant increases for question asking and patient satisfaction. Overall findings re anxiety pre and post consult were not significant and nor was increase in consultation time. Intervention immediately prior to intervention showed stronger/ significant effects on patient satisfaction but also slightly increased the consultation time. Most of the analyses did not differentiate between use of QPL and other methods but it is likely for these there would be no difference in patient satisfaction found. Although meta-analyses used it does raise the issue of pooling such diverse studies.	2007 Review of various pre-consultation interventions to address information needs including QPL; 1) notes small but significant increase in question asking and patient satisfaction for the studies overall ($p<0.01$) 2) Many QPL studies included were combined interventions and QPL studies were not analysed separately 3) For studies including QPLs only no consistent difference in patient satisfaction is likely to be found 4) Although a small increase in consult time is noted across the studies it was not significant.	UK & Australia
Parker, P.A. et al.	2005	What do we know about facilitating patient communication in the cancer care setting	Literature review	Emerging practice	NA - no systematic search strategy but comprehensive coverage of major articles	Literature review re knowledge regarding improving patient / doctor communications. Overall, the empirical literature suggests that some types of patient-based interventions (e.g. prompt sheets, audiotapes, coaching sessions) may be beneficial in specific areas (e.g. increasing the number of questions asked, increased patient satisfaction). However, there are few consistent findings and the outcome measures that have been examined have varied substantially across studies. More controlled studies using carefully chosen outcome variables are needed. Increasing patients' communication skills so that their goals are met has the potential to positively affect the communication process. With regard to QPLs indicates there are no consistent findings in the total number of questions asked but notes that 2 studies report an increase in specific types of questions asked (e.g. prognosis). Notes no association between the number of questions asked with patient satisfaction or with patient speaking times has been reported.	Review (2005) re interventions to doctor-patient communications including QPLs: 1) no consistent findings re an increase in total QA 2) two studies report increase in specific areas of QA (e.g. prognosis) 3) No association between the number of questions asked and patient satisfaction	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Rodin, G. et al.	2009	Clinician-patient communication: a systematic review.	Systematic literature review	Promising practice	Four existing guidelines, eight systematic reviews and nine randomized trials were identified	A systematic review of practice guidelines, systematic reviews, or randomized trials on this topic was conducted. Overall, the evidence suggests that the way that a clinician and treatment team relates to and communicates with patients can have a profound impact including on their psychosocial adjustment, decision making, treatment compliance, and satisfaction with care. Techniques to increase patient participation in decision-making were associated with greater satisfaction but did not necessarily decrease distress. Evidence regarding the benefit of decision aids or communication aids to facilitate better communication is inconsistent. The evidence reviewed in this paper suggests that no single strategy or collection of strategies works best for clinician – patient communication in cancer care. Re findings for QPL there was limited evidence for the effectiveness of QPL interventions (see next column). Notes a study by Butow et al. (2004) where increased QA was found (p=0.001) for intervention subjects although a behavioural analysis of the consultation transcripts revealed similar rates of active patient behaviour across groups, and there were no significant differences in physician behaviour. Although there is increasing evidence to support a number of general approaches, how the interaction unfolds must be individualised to meet patient communication preferences and styles. Few studies took cultural and religious diversity into account. Since patients vary in their communication preferences and desire for active participation in decision making, there is a need for the Dr to individualize communication style.	Systematic Review (2009) clinician-patient interaction, cancer. 1) QPL was found to increase the number of total questions asked by patients (2 trials) or specifically related to the prognosis (1 trial) 2) QPL was associated with no increase (1 trial) or a decrease (1 trial) in patient state anxiety. 2) One trial with a combined intervention including QPL found the intervention group was significantly more anxious than the control group at pre-consultation (p=0.04).	Canada
Ryan, H. et al.	2005	How to recognize and manage psychological distress in cancer patients.	Systematic literature review	Acceptable practice	Not stated	This literature review identifies the main barriers to recognizing emotional distress in cancer patients, and proposes methods to improve the elicitation of emotional cues and the accuracy of identifying distress and psychological morbidity within a cancer consultation. Cites a recent study (Brown et al., 2001) found that cancer patients who were given a question prompt sheet shortly before their first consultation with an oncologist asked more questions, and were given more information about prognosis by their oncologists. Importantly, the study showed that when only the prompt sheet was provided, patients' anxiety increased and consultations were longer. However both these trends were reversed when the oncologist specifically endorsed and addressed the prompt sheet. Therefore, it is essential for faciliatory material to be used appropriately.	Review (2005) re recognition and management of psychological distress in cancer patients. Cites Brown et al., 2001 findings concerning the effectiveness of Dr endorsement of QPLs. The study showed that when only the prompt sheet was provided, patients' anxiety increased and consultations were longer. However both these trends were reversed when the oncologist specifically endorsed and addressed the prompt sheet.	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
Spiegle, G. et al.	2013	Patient decision aids for cancer treatment: are there any alternatives?	Systematic literature review with meta-analysis	Supported practice	24 RCTs	Compared decision support interventions - patient decision aids ((pDA) which present treatment options to patients to elicit a decision and other decision support interventions (ODSI) such as the use of QPLs, booklets, audiotapes that are used to enhance participation in the consultation more broadly. Twenty four studies of Decision Support Interventions met the inclusion criteria and main reason for exclusion was not being an RCT. The studies overall showed that the interventions increased patient knowledge (small but significant effect- but no 'QPL only' studies included here) and question asking. However, anxiety and decisional conflict scores were no different to control subjects receiving usual care. Similarly there were no differences in patient satisfaction. Overall there were no differences in effectiveness between PDA and ODSI studies concerning knowledge, patient satisfaction, anxiety or decisional conflict outcomes. It showed that less complex ODSIs such as QPLs and audio-recording were as effective as pDAs with regard to question asking and knowledge recall. Due to the variation in outcome measures across studies some comparisons are based on only 7 or so studies. Effects of QPLs not analysed separately to studies with brochures and booklets.	Systematic Review (2013) of patient decision aid interventions and other decision support interventions, including QPL, the latter based on 3 studies: 1) Small but significant difference in total question asking ($p<0.05$) reported in 3 studies, 2) no significant differences for anxiety and patient satisfaction 3) Across the group classed as 'other DSI' there was a significant improvement in patient knowledge but this analysis included 4 audiotape studies and only 1 QPL.	Canada
Tattersall, M.	2003	Enhancing communication in the lung cancer consultation.	Literature summary	Expert opinion	Cites 3 QPL RCTs	Summarises use of communication aids, e.g. audio-taping, consultation summaries; to improve patient consultation information. Discusses use of audio-taping to assess outcomes of interventions such as QPLs and consultation preparation packages, and reports 3 trials where increased question asking about prognosis was found. Noted, however, a minimal effect on question asking concerning the evidence base for the proposed treatments and discusses the potential use of a pDA for lung cancer. Discusses the analysis of information provided in referral letters to oncologists and identifies the need for more comprehensive information provision and better letter writing skills.	Brief Summary re enhancing communication for lung cancer. Notes 3 trials where there was an increase in question asking concerning prognosis	Australia
van der Meulen, N. et al.	2008	Interventions to improve recall of medical information in cancer patients: a systematic review of the literature.	Systematic literature review	Promising practice	10 studies selected	Systematic review but interventions too diverse to pool data - so a best evidence synthesis. 43 studies possibly met 7 inclusion criteria and 10 studies were included but 2 were classed as low quality. Interventions included audiotape/videotape (7); audiotape vs. letter (1); summary letter (1) QPL (1). Of the 10 studies selected using rigorous criteria only one tested a QPL intervention (Brown et al., 2001) and most concerned the provision of audiotapes of the consultation to interventions subjects. Audiotape of the patient's consultation enhanced	Systematic Review (2008) re interventions to improve recall. Notes 1 study indicated a QPL (Dr endorsed) intervention had a positive effect on knowledge recall (Brown et al. 2001)	

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Significance of Effect	Country
						recall but a general tape did not. QPL had a positive effect on recall if endorsed by clinician - but only 1 study included. No effect of written summary - only 1 study. Time of recall varied widely across studies. Authors noted the conclusions overall are based on sparse data.		
Watson, P. W. et al.	2009	A systematic review of interventions to improve recall of medical advice in healthcare consultations.	Systematic literature review	Promising practice	34 papers met inclusion criteria	Thirty-four papers were examined but the studies were too diverse to permit meta-analysis. Nine recall interventions were evaluated - 10 studies concerned audio-taping, 10 concerned written materials but only 2 examined QPLs (Butow et al., 1994 and Brown et al., 2001) and these had conflicting findings re recall. The majority of studies concerning audiotape and written material did support small increases in recall but the findings were equivocal possibly due to heterogeneity in intervention design and the chosen period for recall. Concerning the design of these interventions the authors suggest that such cognitive interventions should be based on a more over-arching psychological model concerning memory and recall.	Systematic Review (2009) interventions to recall medical advice. Only 2 QPL studies included Butow et al., (1994) and Brown et al., (2001) and these had conflicting findings	

Table 7 Grey Literature Articles Pertaining to Question Lists

Author / corporate author	**Year**	**Title**	**Organisation**	**Country**	**Document type**	**Purpose**	**Summary**	**Comment**
Ahmed R. et al.	2014	Development of a question prompt list for parents and carers of children diagnosed with attention-deficit/hyperactivity disorder	University of Sydney	Australia	Web-based document	Inform general readers of a new study	The team developed a question prompt list (QPL) as a way of addressing the information needs of parents and carers of children with ADHD. The team won an award for their work. The team worked with parents of children with ADHD, ADHD consumer advocates, clinicians and researchers, nationally and internationally. The QPL is currently being evaluated by parents of children with ADHD to ensure its accuracy and usability.	No study results available at this point. Work continuing on QPLs from University of Sydney work.
Brown, R.	2014	Developing an Online Clinical Trial Specific Question Prompt List	Virginia Commonwealth University	USA	Web-based document	Clinical Trial Registration	Patients will use an online QPL-CT to prioritize their questions and the prioritized list will be conveyed to their oncologist. Investigators will evaluate the efficacy of the online QPL-CT to increase question asking, patient understanding of trial information and reduce patient's conflict over their upcoming decision to join a trial.	No study results have yet been posted. This is a study outline.
Bruce, N. et al.	2008	Models for engaging consumers and clinicians in policy: rapid reviews	Health Issues Centre, La Trobe University; The Sax Institute; NSW Department of Health	Australia	Report	Evidence check/review of the literature to inform policy.	Document aims to answer three review questions relating to 1) community participation tools and consumer engagement, 2) community participation tools and the engagement of special interest groups (Aboriginal and Torres Strait Islander People, CALD groups, people with disabilities, youth and families with young people, people with mental health conditions) and 3) the use of internet based consultations to improve community engagement.	This review examined the broad field of SDM as it relates to community participation. QPLs found to be an effective way to engage consumers in shared decision-making.

Author / corporate author	Year	Title	Organisation	Country	Document type	Purpose	Summary	Comment
Butow, P.	2013	Getting the information needed – What research tells us	Centre for Medical Psychology and Evidence-based Medicine (CeMPED), University of Sydney	Australia	PowerPoint presentation	Inform audience (health professionals, academics, health policy staff) in relation to the evidence for, and use of, QPLs and question coaching	This presentation is by an expert in the field and provides an argument for the use of QPLs and coaching. Patients have information needs for which there are challenges to meet. Looks at evidence from the Kinnersley (2007) review. Introduces QPLs developed by CeMPED. Describes coaching interventions. Examines the findings for meta-analysis on coaching. Effects of coaching and QPL were similar but there was some evidence for shorter consultation time and greater satisfaction. Considers the evidence for cancer specific QPLs (Dimoska et al. 2008, Clayton et al, 2007). Introduced the 3 Questions concept by Shepherd et al (2011) and stated that this was successful. Asked final questions: How long should QPLs be? When should they be given? Should they be general or specific? Should they be tailored or patient derived? Is coaching necessary? What would make coaching more effective?	The final questions are something that should be noted as these are issues raised by this report. The presentation promotes the use of QPLs and coaching as a way to help patients get the information they want.
Cancer Institute NSW	2011	Achievements in Cancer Services and Education 2010	Cancer Institute NSW	Australia	Report	Summary of key achievements against the four program areas identified by the Cancer Plan: 2007-10.	The report identifies comprehensive patient support as one of the four key programs of the Cancer plan 2007-10. A key achievement outlined in the report under this program was the development of 4 question prompt lists for patients to ask oncologists, surgeons, haematologists and complementary therapists. The QPLs were translated into 20 languages and community consultation re: cultural appropriateness is being undertaken. The QPLs were also noted as an important community engagement tool. Consultation on cultural effectiveness is reported but there was no consultation reported concerning the general effectiveness of the QPLs or concerning what questions people actually want to ask.	This is an overview and does not provide any specific data relating to the QPLs. The QPLs are considered as tools for both patient support and community engagement.

Author / corporate author	Year	Title	Organisation	Country	Document type	Purpose	Summary	Comment
Clayton, J et al.	2005	Asking questions can help: a randomised controlled trial of a patient/ caregiver question prompt list for advanced cancer patients being referred for palliative care	Collaboration between University of Sydney, seven palliative care services within greater Sydney and one palliative care service in Adelaide	Australia	Conference abstract	Brief study outline for an academic audience	Presentation on an RCT of a QPL for patients referred to a palliative care service. Aimed to evaluate impact of QPL on the consultation. QPL patients asked twice as many questions (P<0.0001), discussed 23% more issues (P<0.0001). QPL patients asked more prognostic question (P=0.004), were more likely to discuss prognosis (P=0.003) and end of life issues (P=0.001). Fewer QPL patients had unmet information needs about the future (P=0.04). QPL consultations were longer than routine consults by 7 minutes (P=0.002). There were no differences between groups re: anxiety and patient satisfaction.	Refer published article in Table 1 (Clayton et al, 2007)
Epstein. R.M. & Street. R.L.	2007	Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering.	National Cancer Institute	USA	Report	Focus of document is on optimising communication processes between patients/family and health care delivery teams and not just the patient-physician dyad.	Patient question asking is identified as an 'active patient communication behaviour' and is endorsed as a strategy for patients to use to more actively engage with and build effective rapport with their health care clinicians. Effective information exchange is seen as a process of mutual influence between patient and clinician where clinicians empower patients to ask questions. Encouraging patients to ask questions as part of discussions regarding 'bad news' regarding diagnosis and prognosis in cancer care was seen as important in reducing patient distress. The link between communication and improving patient health outcomes was investigated. QPLs and PQPLs are both identified in the document as important communication strategies for improving communication between patients and health care clinicians.	This monograph is a useful general resource for clinicians on the complex process of improving communication between patients/family and health care delivery teams. QPL and PQPL are mentioned in the document as important communication strategies that can be used in combination to a range of strategies to improve communication.
Fischer, M. & Ereaut, G.	2012	When doctors and patients talk: making sense of the consultation.	The Health Foundation	UK	Report	To report on research-based consultations with experts, health professionals and patients concerning doctor-patient communication.	This is a comprehensive research report on consultations with experts in patient-doctor communication, health professionals (including nurses, doctors and other health professionals) and patients. Key themes are presented. Methods include interviews with key individuals and workshops with patients and health professionals. Results of a brief literature scan are also included.	This report discusses issues relating to asking questions in consultations, both by the doctor and the patient but does not go into the development of QPLs. May be a good background document to inform the development of a QPL.

Author / corporate author	Year	Title	Organisation	Country	Document type	Purpose	Summary	Comment
Gramling, R. et al.	2012	What Is Known About Prognostication in Advanced Illness?	None	USA	Book Chapter	To promote the importance of discussing prognosis as an essential component of patient-centred end of life care. QPLs are tools that can be used in this context.	This chapter discusses the issues relating to prognosis. The authors state that QPLs are a tool that can be used in the process of the clinician engaging with the patient in a prognosis conversation. Main topics discussed include an introduction to the problem, a summary of evidence, suggestions for practice and next steps for research. An example of a question prompt list is provided. The QPL has four questions related to cancer prognosis, including: future abilities, shortened life span, time frames and best and worse case scenarios	In relation to 'practice' the authors suggest that question prompt lists can help patients and families to participate. The authors make a very important point regarding the use of QPLs; ie that they can be a useful communication tool, however they are not essential in patient-centred care, nor are they a substitute for effective human interaction in the conversation.
Health Issues Centre & Vic Dep't Human Services	2007	A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services	Health Issues Centre & Victorian Department of Human Services	Australia	Report	This is a policy outline document	This document outlines the evidence for consumer and carer participation in relation to cancer services in Victoria. It includes a summary of a literature review and consultations with consumers and carers as well as a strategic planning section building on evidence presented. Brief, summarised evidence is presented relating to the use of QPLs. QPLs are promoted as a way to increase consumer and carer participation.	Promotes the use of QPLs as a way to increase consumer participation, however, this is not a main focus of the document.

Author / corporate author	Year	Title	Organisation	Country	Document type	Purpose	Summary	Comment
King, E. et al. (MAGIC)	2013	The MAGIC programme evaluation	The Health Foundation	UK	Report	Describes Ask 3 Questions initiative and shared decision making initiatives. Qualitative evaluation of campaign re Ask 3 Questions.	The Magic evaluation (UK) is largely concerned with initiatives concerning clinical training to implement a shared decision making approach in medical consultations. One approach mentioned is focused on patients - The Asking Three Questions initiative - which is really a 3 Q QPL. It is suggested that patients are encouraged to ask these 3 Questions in GP consultations. These are: 1) what are my options; 2) what are the possible benefits and risks and 3) how can we make a decision together that is right for me. Although there is some feedback concerning the initiative it is largely about the media strategy for the 3Q initiative and there is very little quantitative data about where the initiative was actually tested and whether in fact the patients asked the three Qs outlined. This initiative uses 3 Q suggested from Sheppard et al. (2011) study, but Sheppard et al.'s data was based on simulated patient interviews. This initiative requires some field testing prior to widespread implementation.	Asking 3 Qs Initiative based on Shepherd et al. (2011) - little quantitative data available in the MAGIC report

Author / corporate author	Year	Title	Organisation	Country	Document type	Purpose	Summary	Comment
Office of Public Management and The MAGIC Program	2013	Implementing shared decision making	The Health Foundation	UK	Report	To report on the implementation of Shared decision making initiatives by teams participating in the evaluation General audience with an interest in shared decision making as well as health professionals and those involved in health policy.	As part of the UK-based MAGIC program, three primary care teams and six hospital-based teams implemented several shared decision making initiatives. This report is a qualitative report on seven improvement stories from the first phase of the MAGIC program. One of the initiatives implemented by some of the teams was the 'Ask 3 Questions' initiative. Four of the teams (one primary care and three hospital) implemented the 'Ask 3 Questions' material at various levels from simply providing the material to adapting it and using it proactively with patients. The results of the 'Ask 3 Questions' initiatives implemented by the various teams were reported as part of the overall SDM results, Some points raised are: 1) Communication and decision aids should be short and simple and preferably one page. 2) Information provided was not enough to encourage questions. Patients often didn't understand shared decision making and this needed to be explained and patients encouraged (given permission) to ask questions. 3) Written information was not helpful for those with learning disabilities and low levels of literacy. Film/video-based material may be more effective. 4) There was anecdotal evidence that the 'Ask 3 Questions' material could lead to more collaborative and informed decision making.	See above. Qualitative feedback concerning the implementation of the Ask 3 Questions initiative. Patients need to be encouraged and given written permission to ask questions.
Seubert, D.	2008	Questions Are the Answer: Getting patients involved in their healthcare	Marshfield Clinic	USA	PowerPoint presentation	The focus is the “Consumers and Patients” resources available through the AHRQ website, specifically the “Questions Are the Answer” page.	This is a presentation to promote the use of the AHRQ "Questions are the answer" initiative, including the interactive QPL builder available on the AHRQ website. Includes information about other material for patients who don’t use the internet. The idea of the presentation is to get staff on board and using the material - including the on-line question builder.	The question builder is an effective tool, however is not accessible to those patients with poor computer skills and low levels of literacy. Hardcopy QPLs can be used as an alternative to internet based QPLs. Health literacy courses for adults with low literacy have been developed by Marshfield Clinic and other partner health organisations.

Author / corporate author	Year	Title	Organisation	Country	Document type	Purpose	Summary	Comment
Shepherd, H. & Tattersall, M.	2011	Discussion of treatment options in supportive oncology	None	USA	Book Chapter	To inform Health clinicians, researchers and policy makers about the use of QPLs in the context of SDM and preparing patients for their cancer consultation	This book chapter has a section on question prompt lists under the heading "Preparing patients for their consultation". The section outlines 5 recommendations relating to the implementation of QPLs in Australia including training and education for health providers and other staff about QPLs, allow staff to tailor implementation of QPLs, enlist support of a QPL champion, patients should receive QPL as part of an information pack mailed to them prior to the consultation but supplemented by QPLs handed out by staff, educate patients about the QPL and encourage them to ask for, take and use the QPL.	The authors recommend the use of QPLs in the context of SDM when preparing patients for cancer consultation. Key elements are that: education is required; flexibility is needed for localised implementation; clinical champions are required to promote support of the use of QPLs; target new patients; and patient education.
Stacey, D et al.	2012	Coaching/ guidance in deliberation and communication	International Patient Decision Aids Standards (IPDAS) Collaboration	Canada / USA / Germany	Report Chapter	This chapter provides a review of the literature and a statement of standards for guiding and coaching and refers to the use of QPLs in for guiding and coaching in deliberation and communication.	Review of evidence and setting standards of practice in relation to coaching and guidance of patient communication including the use of question lists. Guiding and coaching aims to help patients make higher quality decisions. One of the strategies used is to enhance patients' skills in communicating with their practitioner by helping patients prepare questions and identify concerns or providing a QPL for use with the doctor.	Useful background set of standards in relation to the development of QPLs and coaching patients in question asking. A QPL is a tool that can be used in the context of patient guiding and coaching.
Thomson, R.	No date	Shared Decision Making in Practice: An Overview of MAGIC	MAGIC Cardiff and Newcastle	UK	PowerPoint presentation	A presentation of the MAGIC shared decision making program	Introduces shared decision making and provides an overview of the MAGIC program. Looks at decision aids, option grids etc. and their outcomes. Provides an overview of the "Ask 3 Questions" tool. 'Ask 3 Questions' is part of the MAGIC program. The three questions are: 'What are my options?', 'What are the possible benefits and risk?' and 'How can we make a decision together that is right for me?' Patients are also encouraged to write down other questions they might like to ask. Key messages and wider policy and system issues are presented in relation to shared decision making.	Gives a quick overview of the 'Ask 3 Questions" tool. Outcomes and issues discussed are related to SDM. This presentation highlighted the broader context of QPLs in SDM. Also a key point is that SDM is much more than just tools, it is about a new consumer focussed way of consulting.

Table 8 Question Prompt Lists on the Internet

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
Agency for Healthcare Research and Quality	2010	Get more involved with your Health Care: Do you know the right questions to ask?	Department of Health and Human Services USA	USA	One page 10 questions QPL in both English and Spanish	General medical related questions re tests, treatments, procedures, medication and hospital care. No specific focus on a disease or stage of illness.	Patients who require general advice from a doctor. Not disease specific.	A basic list of questions regarding medical care. Patients could choose appropriate questions from the list of 10 that may apply to their current medical care needs. Simple language.	A simple, user-friendly QPL with a general focus in both Spanish and English.
Agency for Healthcare Research and Quality	No date	Questions to Ask Your Doctor	Cleveland Clinic	USA	A two page document that can be printed from the website.	QPL broken into sections so patients can go to the section that most applies to them at the time.	Patients who are going to attend one of the Cleveland Clinics for general health care	QPL contains a total of 44 questions, divided into the following sub-sets of questions under the headings: Symptoms or Diagnosis (15Q); Treatment (15Q); Surgery (14Q). As QPL is general many of the questions will not apply to people at the one time, but as the QPL is broken down into sections, most of the irrelevant questions can be easily skimmed over.	A useful document for patient who are attending the Cleveland Clinics. This is an organisation specific QPL rather than a disease specific QPL.
Agency for Healthcare Research and Quality	No date	Online Question Builder	Department of Health and Human Services USA	USA	Online interactive document enabling people to create a specific QPL for each medical visit.	To help patients prepare for their next medical appointment by creating a specific list of questions for each visit about a range of medical situations ie: diagnosis, treatment, tests, medications	Anyone who needs to see a doctor.	A helpful tool for someone who is both computer literate and who has a basic level of health literacy. A flexible QPL 'builder' that can be used to prepare for each discussion with a doctor at different stages of health care and for a range of health conditions.	A reasonable level of computer and health literacy is required to use this QPL.
American Cancer Society	2013	Questions to ask my Doctor about breast cancer	American Cancer Society	USA	11 page QPL document that can be printed from the website for use by patients.	A comprehensive list of possible questions that breast cancer patients may want to ask their doctor at different stages of breast cancer.	Breast cancer patients	A QPL with 53 questions for the different stages of breast cancer care from diagnosis (14 questions) through treatment plan (15 questions) to before, during and after treatment (24 questions). Very specific to breast cancer. Could be quite overwhelming but also useful as a comprehensive list of questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	A QPL that is specific to breast cancer. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
American Cancer Society	2013	Questions to ask my Doctor about cancer	American Cancer Society	USA	10 page QPL document that can be printed from the website for use by patients.	A comprehensive and general list of possible questions that cancer patients may want to ask their doctor at different stages of cancer.	Cancer patients in general	A QPL with 47 questions for the different stages of cancer care from diagnosis (15 questions) through treatment plan (12 questions) to before, during and after treatment (20 questions). A general list for any cancer. Could be quite overwhelming but also useful as a comprehensive list of questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	A general QPL for any cancer. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.
American Cancer Society	2013	Questions to ask my Doctor about Colon or Rectum cancer	American Cancer Society	USA	10 page QPL document that can be printed from the website for use by patients.	A comprehensive list of possible questions that colon or rectum cancer patients may want to ask their doctor at different stages of their cancer.	Colon or rectum cancer patients	A QPL with 49 questions for the different stages of colon or rectum cancer from diagnosis (15 questions) through treatment plan (13 questions) to before, during and after treatment (21 questions). Very specific to colon or rectum cancer. Could be quite overwhelming but also useful as a comprehensive list of questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	A QPL that is specific to colon or rectum cancer. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.
American Cancer Society	2013	Questions to ask my Doctor about Lung cancer	American Cancer Society	USA	10 page QPL document that can be printed from the website for use by patients.	A comprehensive list of possible questions that lung cancer patients may want to ask their doctor at different stages of their cancer.	Lung cancer patients	A QPL with 48 questions for the different stages of lung cancer from diagnosis (15 questions) through treatment plan (12 questions) to before, during and after treatment (21 questions).Very specific to lung cancer. Could be quite overwhelming but also useful as a comprehensive list of questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	A QPL that is specific to lung cancer. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
American Cancer Society	2013	Questions to ask my Doctor about Melanoma	American Cancer Society	USA	11 page QPL document that can be printed from the website for use by patients.	A comprehensive list of possible questions that melanoma patients may want to ask their doctor at different stages of their cancer.	melanoma patients	AQPL with 53 questions for the different stages of cancer care from diagnosis (15 questions) through treatment plan (13 questions) to before, during and after treatment (25 questions). Very specific to melanoma and separate from the QPL on skin cancer (Basal and Squamous Cell). This could be confusing for patients who are not sure of the difference between these cancers. Could be quite overwhelming but also useful as a comprehensive list of questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	A QPL that is specific to melanoma. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.
American Cancer Society	2013	Questions to ask my Doctor about Prostate Cancer	American Cancer Society	USA	11 page QPL document that can be printed from the website for use by patients.	A comprehensive list of possible questions that prostate cancer patients may want to ask their doctor at different stages of their cancer.	prostate cancer patients	A 56 questions QPL for the different stages of prostate cancer from diagnosis (20 questions) through treatment plan (13 questions) to before, during and after treatment (23 questions). Very specific to prostate cancer. Could be quite overwhelming but also useful as a comprehensive list of questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	A QPL that is specific to prostate cancer. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.
American Cancer Society	2013	Questions to ask my Doctor about Skin Cancer (Basal and Squamous Cell)	American Cancer Society	USA	11 page QPL document that can be printed from the website for use by patients.	A comprehensive list of possible questions that skin cancer patients may want to ask their doctor at different stages of their cancer.	skin cancer patients	This is a 56 questions QPL for the different stages of skin cancer from diagnosis (15 questions) through treatment plan (13 questions) to before, during and after treatment (24 questions). Very specific to skin cancer (Basal and Squamous Cell) but a separate QPL to the melanoma one. This could be confusing for patients who are not sure of the difference between these cancers. Could be quite overwhelming but also useful as a comprehensive list of	A QPL that is specific to skin cancer. A degree of health literacy is required to use the QPL, and due to its comprehensive nature it could potentially be overwhelming for some patients.

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
								questions. Patients choose which questions to ask for each stage so would not need to 'wade through' the whole document each time. A section at the end encourages patients to develop their own additional questions.	
American Heart Association	2013	Doctor Appointments: Questions to Ask Your Doctor	American Heart Association	USA	A two page document that can be printed from the website, however as the document contains web-links it is best used online.	A summary document with the main points for patients to consider when preparing for a visit to the doctor including hints for how to improve communication. Links throughout the document lead the patient to specific QPLs.	Patients with or at risk of heart disease and / or stroke	A useful overview document with the main points for patients to consider when preparing for a visit to the doctor. Links throughout the document lead the patient to specific QPLs.	A little hard to navigate to find exactly the QPL that the patient may want. Some good general information re improving communication with your doctor, seeking a second opinion and how to find another doctor.
Cancer.Net Editorial Board	2011	Questions to Ask the Doctor	American Society of Clinical Oncology	USA	A three page document that can be printed from the website	Document contains key messages about asking Doctors questions and useful information about how best to communicate with your Doctor and how to use the QPL. QPL broken into sections so patients can go to the section that most applies to them at the time.	Cancer patients in general	QPL contains a total of 57 questions, divided into the following sections: General Information (8Q); Symptoms (5Q); Diagnosis (8Q); Staging (4Q); Treatment (14Q); Clinical trials (9Q); Support (7Q); Follow-up care (2Q). Other cancer type specific questions can be accessed via a link to different cancer types.	Many questions for people to choose from so it could get a bit overwhelming. Some good, simple explanations provided for 'medical terms' to help patients with a low level of health literacy understand the suggested questions.
Health New England	No date	Questions to Ask Your Healthcare Provider	Health New England	USA	A two page document that can be printed from the website.	General information regarding how patients can take an active role their health care by seeing their doctor regularly and asking questions, followed by a QPL covering diagnosis, medications, prevention and wellness,	Anyone who needs to see a doctor.	QPL contains a total of 34 questions, divided into the following sub-set of questions under the headings: diagnosis (15Q); medications (6Q); prevention and wellness (9Q); what's next (4Q). There is space for the patient to write notes next to each question and comment at the end.	This is a simple, easy to use QPL for general discussions with doctors. Having the space for patients to write notes next to each question when they are in the consultation with their doctor enables the one document to contain both the questions and

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
									answers for easy future reference by patients.
John Hopkins Medicine - John Hopkins University	2012	What questions should I ask my doctor	The Sol Goldman Pancreatic Cancer Research Center	USA	A two page document that can be printed from the website.	To encourage patients with pancreatic cancer to not only ask questions regarding their medical condition but to reflect on how responsive the doctor is to their questions.	Patients with pancreatic cancer who are seeing a doctor at one of the John Hopkins Medicine centers.	QPL contains 24 questions under the headings: 'If you are meeting with a surgeon or oncologist for the first time, do not be afraid to ask' - 5 questions regarding the doctor's qualifications and experience in treating pancreatic cancer patients; 'At any point in the relationship with your physician, you have the right to ask' - 12 questions regarding diagnosis, treatment options, medication, clinical trials and diet; 'Do not forget to ask about the things that are most important to you' - 4 questions regarding the impact of the treatment on the patient's life; 'Finally - and most importantly - ask these questions of yourself' - 3 questions reflecting on the doctor's response to the patient's questions.	This QPL is different from others as the focus is not purely on helping patients to seek information from their doctor about the medical condition and treatment, but also encouraging them to ask about the impact on the treatment on work / life / home as well as reflection by the patient regarding how they feel about the doctor's communication style.
National Family Caregivers Association	No date	Questions to Ask Your Healthcare Provider	National Family Caregivers Association	USA	A two page document that can be printed from the website.	QPL for family carers to use regarding general medical / hospital procedures. The focus is not on the patient asking the questions of the doctor but the carer asking the questions on behalf of the care recipient.	Family carers who need information about general medical / hospital care for the person they are caring for.	Questions in this QPL are focussed on information the family caregiver needs on behalf of the care recipient. The 48 questions are organised by the following categories: 'About medical care in general' - 13 questions regarding diagnosis, treatment and impact on care recipient; 'About Medical Tests and Procedures' - 14 questions regarding consent by care recipient, and impact on care recipient of tests; 'About how the doctor's office works' - 6 questions regarding the logistics of contacting the doctor; 'Costs of Medical care' - 5 questions regarding costs / insurance; 'Discharge Planning' - 8 questions regarding extra care in the home and if the person needs to go to another care setting either permanently or temporarily.	A useful QPL for family carers who need information regarding health care for their care recipient. The suggested questions cover not only medical information but also the impact of the care recipient's illness on the carer.

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
National Heart Lung and Blood Institute	No date	Questions To Ask Your Doctor If You Have High Blood Pressure	Department of Health and Human Services USA	USA	One page on website with 14 questions - could be printed.	To encourage patients with high blood pressure to ask questions regarding blood pressure management, medication and lifestyle risk factors.	People with high blood pressure	14 questions relating directly to diagnosis, clarification of what the 'goal' blood pressure is for the patient and management of high blood pressure including medication, diet and exercise.	A simple, easy to use QPL. The inclusion of a question re 'goal' of medical treatment / management is a good way to help the patient focus the discussion with the Doctor around a specific goal for medical treatment. Questions regarding lifestyle factors such as diet and exercise are also included as they are relevant to the management of high blood pressure.
University of California San Francisco Medical Centre	2002	Women's Health Checklist: Questions to Ask Your Provider	University of California San Francisco Medical Centre	USA	One page on website with 14 questions - could be printed.	General questions regarding women's health issues, tests, treatments and medications.	Women who are seeing their doctor about a range of health matters.	QPL has a total of 28 questions under the following headings: 'general health and wellness' (6Q); 'medical tests' (6Q); 'symptoms and diagnosis' (4Q); 'treatment' (8Q); 'medication' (4Q). The QPL suggests also asking a pharmacist the medication questions Simple language used.	Although broad in scope of the topics covered by the questions, this is a relatively simple and user-friendly QPL for women's health.
Australian QPLs									
Asthma Australia	ND	Ten things to ask your Doctor	Asthma Australia	Australia	One page with web-links for more information regarding each question	To provide information and guidance to asthma patients in getting more information.	Asthma patients who are going to see their doctor	This is a succinct QPL targeted at asthma patients. There are web links for some question so if patients want more information about the topic they can go to that page and get more information to help them better understand the issue e.g.: exercise, medication and asthma management plans.	This is a simple, user friendly QPL for asthma patients. However, as it is web based it is not accessible to those who are not computer literate or who do not have internet access.
Australian Cancer Trials and University of Sydney	2010	Should I consider joining a clinical trial?	Cancer Australia	Australia	web-based	To educate and inform patients thinking of joining a clinical trial.	This QPL is for cancer patients who are thinking of joining a clinical trial.	This QPL provides a list of 20 questions under the headings: Understanding my treatment choices; Finding out about a trial; Understanding possible benefits; Understanding the possible risks; The differences between going on the trial and standard treatment; Types of clinical trials	This QPL appears to be somewhat user friendly; however, a certain amount of literacy, health literacy and computer literacy is needed.

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
								and understanding 'randomization' and 'blinding'; Understanding my right to join or not to join the trial; and Results of the trial. Patients can click on specific terms (e.g. 'benefits', 'general risks', 'randomization') to get an explanation or further information. Patients are told that they will not find all the answers to the questions from the Cancer Trials website and to print out those questions they don't have answers to and ask their cancer specialist	Explanations and further information is given for some terms. Access to a computer, the internet and a printer are required. No recommendation to get help from another person to use the QPL is given; however, to use a web-based tool would require a level of skill enough to also use the tool.
Australian Cancer Trials and University of Sydney	2010	Should I Consider Joining This Clinical Trial?	Cancer Australia	Australia	Web-based	To educate and inform patients who have decided to join a particular clinical trial.		This QPL of for patients who have chosen to join a clinical trial that interests them. It contains 34 questions under the headings: Understanding my choices; Finding out about this trial; Understanding the trial's purpose and background; Understanding the possible benefits; Understanding the possible risks; The differences between going on the trial and not going on the trial; Understanding how the trial is being carried out; Understanding the type of trial and 'randomization'; Understanding my right to join or not to join the trial; Understanding possible conflict of interest (for your cancer specialist); Results of the trial. Patients are encouraged to print out and bring the QPL with them to their cancer specialists and to ask those questions they couldn't find answers for from the Australian Cancer Trials website. There are a number of terms throughout the QPL that can be clicked to bring up further information or explanation.	While there are 34 numbered questions in the QPL, several questions contain more than one question (sometimes up to three) giving an actual total of 42 questions. There are a number of terms that will need explanation throughout the QPL with some of them able to be clicked to get more information. A certain level of literacy, health literacy and computer literacy would be needed to use this tool as well as access to a computer, the internet and a printer.
Cancer Australia	2013	Cancer —how are you travelling? Understanding the emotional and social impact of cancer.	Cancer Australia and National Breast and Ovarian Cancer Centre	Australia	Report	To provide information about the social and emotional impact of cancer	People diagnosed with cancer, their family and friends	This booklet contains a question prompt list at the end of the booklet that was adapted from work done by the school of Psychology, University of Sydney (Butow and Grivas, 2004). The QPL contains 52	This QPL is similar to the QPLs for the Cancer Institute NSW due to their development by the

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								questions under the headings: Diagnosis, Care, Treatment information and options, How can I help, The future and Support Information. Questions have a tick box for patients to use as well as space at the end to write their own questions.	same Sydney university team. The QPL appears in a four page section as the end of the booklet. This may not be as accessible for patients as a one page document. There are similar issues as with the other Sydney University work including the length of the QPL and some double barrelled questions. Further research on which questions patients are most likely to ask and what order they should come in may be of benefit.
Clayton, J and Butow, P	2006	Asking questions can help: an aid for people seeing the palliative care team	Medical Psychology Research Unit, University of Sydney	Australia	Booklet	To provide palliative care patients with some information and questions to ask their palliative care doctor.	Patients who have been referred to the palliative care team.	After a brief introduction they provide a list of 112 questions for the patient to ask. They are divided up into sections with descriptive headings and lines for extra questions to ask. Sections and subsections include 1) About the Palliative care service and team 2) Available care 3) Contacting the palliative care team (PCT) 4) Relationship between PCT and other health professionals. 5) Physical symptoms. 6) Treatment - Medications, morphine. 7) Lifestyle & QoL 8) My illness and what to expect in the future. 9) Support - information, practical support, financial support, emotional support, spiritual/cultural support. 10) If you are concerned about your professional care. For carers: End of life issues - short introduction and Questions the patient may like to ask; Questions my carers or family may like to	This is a long QPL. Query whether placing questions about the palliative care team at the front is desirable. Patients may be tempted not to carry on to the following questions that may be more important for them. It may be better to have these questions near the end. There are many questions so it may be more appropriate for the PCT to simply provide information about some aspects. Patients may

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								ask. The number of questions in each section ranged from 2 to 11.	experience information overload from the range of topics introduced by the questions.
Northern Territory Department of Health	2014	The Cancer Journey	Northern Territory Department of Health	Australia	Web page	To inform and support patients with cancer	For patients recently diagnosed with cancer	The webpage provides a list of questions that patients diagnosed with cancer may wish to ask their clinician. There is a list of 11 example questions for patients. Questions focus on treatment issues, effects of the cancer on the person and their life/lifestyle, whether the cancer has spread and further tests. The webpage also refers to the QPLs developed by the Cancer Institute NSW “asking questions is important” as a resource for more questions to ask at different points of the cancer journey.	This is an example of a short QPL provided on a website that may have been adapted from the work done by Sydney University and the Cancer Institute NSW. The reasons for the selection of these specific questions is not clear as they are only given as an example. Patients are then pointed to a more in-depth resource.
Peter MacCallum Cancer Centre	2009	Questions about Chemotherapy	Peter MacCallum Cancer Centre	Australia	One page	To be given to cancer patients about to undergo chemotherapy. The QPL is to be given to them before a chemotherapy education session.		This is a QPL for cancer patients who need chemotherapy treatment. There are 27 questions appearing under the following headings: How is chemotherapy given; What does chemotherapy feel like; Ways of reducing your risk of infection; Managing fatigue; Reducing nausea and vomiting; managing constipation and diarrhoea; Taking care of your mouth. There are between 3 and 6 questions under each heading. There are tick boxes that allow patients to tick questions relevant to them. This QPL is to be used in conjunction with a DVD "Looking after yourself during chemotherapy". Patients are encouraged to bring both the QPL with questions ticked and the DVD to the education session. Space on the back of the page is provided for patients to write more questions.	This is the first QPL that has been designed specifically to be used with a DVD. The questions are focussed on the chemotherapy process, symptoms and self-care. No questions re: future aspects such as long term side effects.

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The Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)	2008	Questions to ask your medical or radiation oncologist	University of Sydney and Cancer Institute of NSW	Australia	Pamphlet	To be given to oncology patients before a consultation	Patients with cancer going to see their oncologist that day.	This is an updated version of the previous pamphlet of the same name. There is a circle that patients tick for questions they want to ask. The number of questions is 49. Questions appear under a number of sections, which have some changes from the previous QPL. Headings are: Diagnosis, Tests, Prognosis, Treatment options, Treatment plan, Preparing for treatment, Clinical trials, Costs, Optimal care, Multi-disciplinary teams, and Support information. Number of questions per section ranged from 2 to 8 questions. Prognosis had the most questions (8). This pamphlet is also provided in large print and translated into the following 20 languages: Vietnamese, Turkish, Spanish, Serbian, Russian, Portuguese, Polish, Persian, Mandarin, Macedonian, Korean, Khmer, Japanese, Italian, Indonesian, Greek, Croatian, Cantonese, Assyrian and Arabic.	This pamphlet has been updated from the previous version of the pamphlet possibly to reflect the questions that patients are more likely to ask. The section on 'How and when to questions' no longer appears. Some questions have been moved but have not been deleted. Some double barrelled questions have been split but not all. Double barrelled questions still appear.
The Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)	2008	Questions to ask your haematologist	University of Sydney and Cancer Institute of NSW	Australia	Pamphlet	To be given to haematology patients before a consultation	Patients with cancer going to see their haematologist that day.	This is disease and treatment specific QPL tailored for patients with cancer. There is an initial introduction and then a list of 52 questions under relevant headings. The headings are the same as for the oncology QPL although there are additional questions about dental care and tests. The number of questions in each section ranges from 2 to 8 with prognosis having the most questions (8). This pamphlet is also provided in large print and translated into the following 20 languages: Vietnamese, Turkish, Spanish, Serbian, Russian, Portuguese, Polish, Persian, Mandarin, Macedonian, Korean, Khmer, Japanese, Italian, Indonesian, Greek, Croatian, Cantonese, Assyrian and Arabic.	This is a treatment specific QPL that allows patients to tick the questions they want to ask and provides space to write additional questions. With approximately 50 questions, this QPL may be quite long for patients and may suggest a number of questions they may not find relevant or remember. It is not clear as yet if a comprehensive list or a succinct list of only the most relevant questions would be better.

Author / corporate author	Year	Name of Document	Organisation	Country	Type of document	Purpose	Audience	Summary	Comment
The Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)	2008	Questions to ask a surgeon	University of Sydney and Cancer Institute of NSW	Australia	Pamphlet	To be given to patients before they visit their surgeon.	Patients with cancer going to see their surgeon that day.	This is a disease and treatment specific QPL tailored for patients who need surgery for their cancer. There is a list of 45 questions appearing under a number of headings including: Diagnosis, Tests, Prognosis, Treatment options, Surgery plan, Effects of the surgery, Costs, Optimal care, Multi-disciplinary teams and Support information. Each section has between 2 and 7 questions. The 'effects of the surgery' section has the most questions (7). This pamphlet is also provided in large print and translated into the following 20 languages: Vietnamese, Turkish, Spanish, Serbian, Russian, Portuguese, Polish, Persian, Mandarin, Macedonian, Korean, Khmer, Japanese, Italian, Indonesian, Greek, Croatian, Cantonese, Assyrian and Arabic.	This pamphlet is an update of the previous 'Questions to ask a surgeon' pamphlet. The questions are mostly the same but the section on 'How and when to ask questions' has been dropped and an additional question has been included in the 'tests' section.
The Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)	2009	Questions to ask about complementary therapies	University of Sydney and Cancer Institute of NSW	Australia	Pamphlet	To be given to patients before they visit a health professional about their cancer. Not clear about when this pamphlet is given to patients.	Cancer patients who are visiting their health professional (doctor, therapist or other HP).	This is a treatment specific QPL aimed at cancer patients with questions about complementary therapies. There is a short introduction with a list of things to consider about complementary therapies. Following this there is a list of 49 questions under the following headings: General questions to ask any complementary therapist, General questions to ask your doctor, Questions to ask your health professional about specific therapies (Mind body techniques, Body-based practices), Biological-based therapies (Nutrition, Herbal medicine), Other therapies (Flower remedies and homeopathy). Patients can tick the questions relevant to them and/or write their own. The number of questions under each heading range from 2 to 15. General questions to ask a therapist had the most questions (15). This resource has also been translated into the following 20 languages: Vietnamese, Turkish, Spanish, Serbian, Russian, Portuguese, Polish, Persian, Mandarin, Macedonian, Korean, Khmer, Japanese, Italian,	This follows a similar format to the other QPLs by CeMPED but the questions are quite different and tailored to the range of complementary therapies available. The headings allow patients to concentrate on the sections they want. It is not entirely clear to whom these questions should be addressed. There are issues raised concerning the relevance of some of the questions.

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								Indonesian, Greek, Croatian, Cantonese, Assyrian and Arabic.	
The School of Public Health, Queensland University of Technology	2008	It's okay to ask	The School of Public Health, Queensland University of Technology	Australia	Booklet	The booklet is written to help brain tumour survivors, their families and health care professionals.	Brain tumour patients who are visiting	This 33 page booklet provides an initial QPL with some information about asking questions as well as additional questions if patients want to know more. There is some coaching on asking questions before the initial QPL. The initial QPL contains 31 questions on the following topics: Diagnosis, prognosis, symptoms and changes, the health professional team, support, treatment and management, surgery, oral medications, living healthily, complementary and alternative medicines and therapies, and after treatment. There are an additional 150 questions on specific issues that patients may or may not wish to investigate further are provided under topics similar to those mentioned above. According to the booklet it was written with the help of brain tumour survivors, their families and doctors and nurses. Patients are also provided with regular sections for them to write their own questions.	This is a very long QPL, however, patients are not necessarily expected to go through the whole thing. Patients are provided a shorter list first and then additional questions if they want them. The addition of some coaching text at the beginning is different to other QPLs. This QPL aims to be either comprehensive or brief depending on what the patient wants. It can be provided in a printed format but has also been provided in pdf format so it can be read online as well. For patients to write their own questions it would need to be printed. Both the initial and additional questions often include more than one question in each 'question' as well as double barrelled questions.

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University of Sydney and Cancer Institute of NSW	No date	Questions to ask your surgeon	Medical Psychology Research Unit at Sydney University with funding from the Cancer Institute NSW.	Australia	Pamphlet	A question list for patients to be given before a consultation and to take with them into the consultation	Patients who have cancer who need to undergo surgery and are going to see their surgeon that day.	A list of 50 questions is provided in a pamphlet format. A box patients can tick appears at the right of the question. Patients are encouraged to take the list to the consultation. The list of questions are broken down into the following sections and subsections: How and when to ask questions, Diagnosis, Tests, Prognosis, Optimal care, The multi-disciplinary team, Treatment information and options (options, surgery, effects of the surgery, costs, support information). Each section/ subsection has between 2 and 7 questions.	Tick boxes are an easy feature for patients to use. Questions appear on one page so it doesn't appear too burdensome. Questions are tailored for the audience. There are still many questions that patients may not remember or skip. There are a number of double barrelled questions l.
University of Sydney and Cancer Institute of NSW	No date	Questions to ask your medical or radiation oncologist	Medical Psychology Research Unit at Sydney University with funding from the Cancer Institute NSW.	Australia	Pamphlet	A question list for patients to be given before a consultation and to take with them into the consultation	Patients with cancer going to see their oncologist that day.	A list of 49 questions is provided in a pamphlet format. There is a box that patients can tick at the right of each question. The list of questions are broken down into the following sections and subsections: How and when to ask questions, Diagnosis, Tests, Prognosis, Optimal care, The multi-disciplinary team, Treatment information and Options (options, treatment, clinical trials, preparing for treatment, costs, support information). Each section/ subsection has between 2 and 9 questions. Prognosis had the most (9) questions.	This pamphlet is similar to the pamphlet "Questions to ask your surgeon" but with questions tailored for the audience. Similar problems in that there are many questions, some that may be better answered by providing written information (e.g. information about multidisciplinary teams and costs.) Several double barrelled questions.

Table 9 General literature relating to Question Prompt Lists

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Aboumatar, H. et al.	2013	Making hospital care patient-centered: the three patient questions framework.	Expert opinion	Expert opinion	NA	Suggests by the use of 3 questions patients can measure the patient-centredness of hospital in-patient stays. These questions are: Are my needs being met by the hospital; Am I involved in my hospital care and Am I prepared to care for my condition at home.	Patient-centredness of hospital stays	USA
Alden, D. L. et al.	2014	Cultural targeting and tailoring of shared decision making technology: A theoretical framework for improving the effectiveness of patient decision aids in culturally diverse groups.	Expert opinion	Expert opinion	NA	Outlines a theory based framework/guide for those interested in cultural targeting and tailoring to develop and test patient decision aids with a view to improving shared decision making. Suggests use of cultural constructs such as collectivism and individualism to differentially target decision aid content for patients from various cultures. Also suggests tailoring individual information based on measuring how strongly the individual is connected to dominant cultural mindsets. The issues are relevant also to the design of communication aids/decision support interventions including QPL.	Cultural targeting and tailoring	USA
Alden, D. L., et al.	2013	Shared decision making and patient decision aids…	Survey of physicians	Emerging practice	Survey of 140 physicians	Physicians recognised the benefits of pDAs in empowering patients and a paper based brochure with an options matrix was the most commonly used in clinics. Interactive online website with a workbook was most commonly used outside the clinic. Main perceived benefits of use of pDA were: improving patient knowledge and satisfaction with consultation process, improving patient compliance and clinical outcomes, improved patient quality of life and reduced anxiety. PDA also reduced counselling time. DA use among the sampled physicians positively correlated with perceived benefit (r = .36; P < .001) and negatively with perceived barriers (r = -.27; P < .001). Furthermore, while low awareness of DAs was perceived as a barrier, a strong positive correlation was found between current use and awareness (r = .80; p<0.001).	Perceived benefits of patient decision aids	USA
Ashton C.M. et al.	2010	A patient self -assessment tool to measure communication behaviours during doctor visits about hypertension	Usability testing of patient self-assessment tool	Routine practice	8 usability testing, 13 cognitive response testing	Self-assessment tool to test effectiveness of DVD re ABC of communication with your doctor- ask questions, be prepared, express concerns in improving communication in hypertensive patients. Focus is improving communication of special needs patients who have cultural issues and low levels of literacy. Self-assessment tool is administered via a structured interview. 130 questions, so very long. Improving communication skills of low literacy special needs patients may help them to take a more active role in consultations with doctors.	Cross-cultural and low literacy issues	USA
Barr P. J. et al.	2014	The psychometric properties of CollaboRATE: A fast and frugal patient reported measure of the shared decision- making process	Psychometric assessment : SDM scale	Other; emerging practice	Online data: 1341 participants representative of US population characteristics	CollaboRate is a 3 item patient rating scale concerning whether a) explanation of the health issue B) elicitation of patient preferences and C) integration of patient preferences occurred in the clinical encounter. The study assessed the scale's psychometric properties using simulated patient encounters. The scale demonstrated discriminative validity in relation to SDM behaviours, concurrent validity with other measures of SDM, good inter-rater reliability and sensitivity to change. No assessment of internal consistency or explanation of why these particular items were chosen, & will need field testing to explore aspects of divergent validity. Shows promise but further validation is required.	Assessment tool for SDM	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Barratt, A.	2008	Evidence based medicine and shared decision making.	Literature discussion	Expert opinion	NA	Discusses some philosophical tensions/ incompatibilities between the EBM and SDM approaches (integration of research evidence and patient preferences) and discusses some problems in the implementation of these approaches.	Philosophical tensions EBM and SDM	Australia
Bender, J. L. et al.	2008	What patients with cancer want to know about pain: A qualitative study.	Qualitative semi-structured interviews	Emerging practice	18 breast cancer patients	Qualitative study that explored the questions women with Breast Cancer want to ask about pain. Seven themes and 200 questions were identified. As many questions may be difficult to address adequately within a standard consultation author suggest a web site dedicated to this issue. The topic of pain might also be considered for inclusion in a QPL for this area.	Information needs - pain	Canada
Blumenthal-Barby, J. S. et al.	2013	Decision Aids: When 'nudging' patients to make a particular choice is more ethical than balanced, nondirective content.	Expert Opinion	Expert Opinion	NA	Critique which queries whether the content of patient decision aids should be designed to be neutral, unbiased and non-directive as possible. Identifies 3 situations where balance should not always be the goal and suggests that nudging patients towards some treatment options, where evidence is clear, should be considered.	Patient decision aids and EBM	USA
Bouleuc, C. et al.	2010	How to improve cancer patients' satisfaction with medical information.	Expert Opinion	Expert Opinion	NA	Need for a patient centred communication strategy including discussion of treatment options and patient outcomes. Communication and patient-centredness can be facilitated by examination of patient quality of life issues and the use of patient information and decision support tools.	Patient-centred communication strategy	France
Brom L. et al.	2014	Congruence between patient's preferred and perceived participation in medical decision making: A review of the literature	Systematic literature review	Promising practice	44 studies	Literature review of congruence between patient preferences for participation in SDM and perceived participation in decision making. Demographic factors such as gender, age, level of education influence patient preference for involvement in decision making ie: younger, educated females prefer a more active involvement in decision making than older patients. Stage of disease trajectory is also a factor in degree of patient involvement in decision making. Mean of congruence between preference for and perceived participation in decision-making was 60%. Literature review provides valuable context for effective use of QPL. Doctors need to be sensitive to individual patient preferences re communication at the different stages of disease trajectory.	Patient preference for SDM	Netherlands
Cegala D. J. et al.	2009	The impact of patient's participation on physician patient-centred communication	RCT	Acceptable practice	25 GPs and 150 patients	This study examined how patients' active participation (e.g., asking questions, providing information) affects physicians' use of patient-centered communication. When interacting with high participation patients, physicians engaged in significantly more patient-centered communication overall than when interacting with low participation patients (p=0.01) but particularly with regard to exploring the patient's disease and illness experience. Overall, the results show an association between patient participation and physicians' patient-centeredness. Patients who actively participate in medical interviews may have influenced physicians to adopt a more patient-centered style of communication. However, ambiguity remains as to the extent the results are accounted for by ONLY the patients' influence on physicians.	Active patient participation and Dr communication	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Charles, C. et al.	2005	Treatment decision aids: conceptual Issues and future directions.	Literature discussion	Expert opinion	NA	A critique concerning the use patient decision aids (pDA) - choice of pDA needs to be related to the context and goal of treatment at the time of the consultation. The goal of the consultation (e.g. information exchange, value clarification) should drive the selection of the pDA and the selection of outcome measures rather than vice versa - there needs to be more consideration of how and why studies are using a specific pDA and the outcomes measures then used to assess their effectiveness. Notes implicit value assumptions in pDAs and value clarification exercises should be communicated to patients. Not directly related to QPL but the conceptual issues raised may be worth consideration in the design of QPLs and associated evaluation studies.	Use of pDAs and selection of outcome measures - can apply to QPL research	Canada
Coleman, J. et al.	2005	The effect of a frequently asked questions module on a pancreatic cancer Web site patient/family chat room.	Posts before and after web module introduction	Routine practice	600 chat room posts	Analysed the effect of a FAQ module placed on a pancreatic cancer web site by examining chat room posts before and after introduction. Three themes identified; giving and receiving information; support seeking or giving and reporting status or death. Following introduction of FAQ module there were less posts about medical treatment and more posts about prognosis and end of life care ($p<0.01$). Study supports the introduction of the FAQ module but it could further address pain management and end of life care issues.	Website FAQ education module	USA
Clayton, J. et al.	2005	The needs of terminally ill cancer patients vs caregivers for info regarding prognosis and end of life issues.	Qualitative - focus groups	Emerging practice	19 advanced cancer patients; 24 caregivers; 22 health professional interviews	Three themes were identified from focus groups re information needs: the importance and consistency of openness; the need for specific information to care for the patient and the value of having separate discussions with the patient and caregiver. Terminally ill cancer patients and their caregivers have different needs for information about prognosis and end of life issues. The caregiver requires more detailed information than the patient about the dying process as this pertains to their caring role although some patients might also wish to receive this information. Some caregivers wished to protect the patient from full knowledge of their condition. Forms part of the background research that led to a QPL for palliative care.	Information needs - terminal cancer, background to QPL	Australia
Craft, P. S. et al.	2005	Knowledge of treatment intent among patients with advanced cancer: a longitudinal study.	Interviews of advanced cancer patients receiving palliative care; longitudinal	Acceptable practice	181 patients with cancer	Assessed knowledge of advanced cancer patients receiving palliative care concerning diagnosis and the intention to treat. 181 patients were interviewed at entry to palliative care and at a 12 week follow-up. 22% patients considered their illness as not life threatening; 29% thought the intention of treatment was a cure and only 46% saw their treatment as non-curative and these proportions were similar at follow up. Rural patients were more likely to perceive treatment intent as curative. Patients with less than 6 months to live had a clearer understanding that treatment intent was not curative. Many patients did not understand the goals of treatment and excessive optimism may lead to impaired decision making. A need for further research re information transfer and predictors of accurate patient understanding which may facilitate clinical discussion of prognosis and treatment outcomes.	Patient knowledge re diagnosis and intention to treat - advanced cancer	Australia

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Davis, R. E. et al.	2008	How willing are patients to question healthcare staff on issues related to the quality and safety of their healthcare?	Cross sectional study using standardised questionnaire	Emerging practice	80 post surgical patients	Survey examined patient willingness to question healthcare staff about their treatment and their willingness to ask factual vs. challenging questions. Patients were significantly more willing to ask staff factual vs. challenging questions. Drs instructions to ask challenging questions slightly increased patient willingness to ask challenging questions of doctors and nurses (both p<0.01). Women, educated patients and patients in employment were more likely to ask questions overall. Patient involvement strategies need to take into account patient characteristics.	Factual vs. challenging question asking	UK
Davison, B. et al. 2003	2003	Provision of individualised information to men and their partners to facilitate treatment decision making in prostate cancer	One group, pre-post testing	Acceptable practice	74 couples, of which 73 men had early stage prostate cancer.	A computer based program (Patient Information Program - PIP) was used to provide tailored information to men and their partners about what/ about their health information needs. Part 1 of PIP was a computer version of the Control Preference Scale rating whether patients preferred to 'make the final decision themself' down to 'leave all decisions to others'. Part 2 was a health information needs survey. PIP also included an anxiety and depression scale. Patients and partners used PIP separately. No question lists were provided or generated as part of the PIP. Computer-generated, graphic printouts from PIP were used to guide the information counselling session. Respondents completed measures at the time of diagnosis and four months later. Patients reported assuming a more active role in medical decision making than they had originally intended, partners assumed a more passive role in decision making than originally intended, and all participants had lower levels of psychological distress at four months. PIP improved patient decision making and reduced couples anxiety levels. No control group so conclusions are uncertain.	Computer generated program to tailor consultations	Canada
Dear, R.F. et al.	2011	Consumer input into research: The Australian Cancer Trials website	Consumer feedback on website	Emerging practice	47 patient users of the website	The Australian Cancer Trials website (ACTO) was publicly launched in 2010 to help people search for cancer clinical trials recruiting in Australia, provide information about clinical trials and assist with doctor-patient communication about trials. Consumer representative groups were consulted by the research team during the design and development of ACTO which combines a search engine, trial details, general information about trial participation and QPLs. A study of 47 patient users, 89% found the website helpful for learning about clinical trials and all respondents thought patients should have access to ACTO. Consumer input has ensured that the website is informative, targets consumer priorities and is user-friendly.	Website re cancer trials which includes QPLs	Australia
Eggly, S. et al.	2011	Variation in question asking during cancer clinical interactions.	Comparison of consultation data for black and white cancer patients	Routine practice	109 oncology patients; 30 'black' patients, 79 'white'; companion present 80 subjects, no companion 29	Analysed videotaped cancer consultations to investigate whether patient demographic characteristics and presence of patient companions influenced variations in patient question asking in cancer clinical consultations. Black patients asked fewer questions overall and fewer direct questions which suggest they received less information. Black patients were less likely to have a companion present which resulted in fewer questions being asked on their behalf.	Analysis of patient demographic characteristics and presence of companions in relation to question asking	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
					subjects; convenience sample within broader study			
Eggly, S. et al.	2006	Information seeking during "bad news" oncology interactions: Question asking by patients and their companions	Transcribing 28 video recorded interactions from 13 oncologists at two research sites and coding all questions asked.	Emerging practice	28 outpatient 'bad news' interactions	This study investigates questions asked by patients and their companions during stressful 'bad news' encounters in the oncology setting. Findings demonstrated that at least one companion was present in 86% of the 28 interactions and companions asked significantly more questions than patients ($p < 0.001$). The most frequently occurring topics for both patients and companions were treatment, diagnostic testing, diagnosis, and prognosis. Older patients asked fewer questions, while more educated patients asked more questions. With regard to the independent ratings of the quality of the dyadic relationships, results showed that ''trust'' between the physician and the companions was positively correlated with increased QA ($r=0.41$) and ''conversational dominance by physician'' was negatively correlated ($r=-0.56$) with the frequency of companion questions. As patient 'trust' in the Dr increased the number of questions the patient asked decreased but an interaction effect with the companion findings above may be associated with this. The total number of questions asked was significantly related to the length of the consultation.	Patient factors influencing question asking in bad news interactions between oncology specialists and patients. Length of consultation associated with questions asked	USA
El Turabi, A. et al.	2013	Variation in reported experience of involvement in Cancer treatment decision making: Evidence from the National Cancer Patient Experience Survey	UK National cancer patient survey	Other: Acceptable practice	41,411 cancer patients (prior hospital attendees)	Examined proportion of positive responses (Yes, definitely) to Q concerning involvement in decision making (Were you as involved in decisions about which treatment you would have as you wanted?) in the UK Nation Cancer Patient Experience Survey. They compared data across 38 cancers using logistic regression and examined socio-demographic factors. 72% of patients reported positive experiences. Younger patients, very old patients and ethnic minorities reported less positive experiences. Patients with rectal, ovarian, multiple myeloma and bladder cancer reported less involvement in decision making. Explored the effects of adjusting for socio-demographic factors, cancer type and treatment hospital which did not effect the results. Due to lack of severity data unable to case-mix adjust analyses but this is recommended for future research. Clustering of different patient groups within hospital with outlying performance report scores could not account for the observed differences. Authors acknowledge the limitations of survey data and identify areas for further research.	Review of patient decision making involvement in cancer treatment	UK

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Flocke, S. A. et al.	2011	Patient-rated importance and receipt of information for colorectal cancer screening.	Cross-sectional cohort, compared information patients required vs what was given	Acceptable practice	415 patients, 64 primary care physicians	Patients due for colorectal cancer screening completed a pre-visit survey about their information needs. The consultations were audio-taped and analysed for content. Most patients required information about test accuracy, testing alternatives, testing pros and cons and testing process yet the actual consultations rarely addressed these issues save for the testing process. Physicians rarely (5%) asked if the patient had any questions concerning screening. Although half the patients asked questions about screening these were mainly about the screening process and did not fill the gap between patient expressed importance of information and physician provided information. Information gaps may potentially adversely affect the uptake of screening by patients.	Information needs identification for colorectal screening. Physician's rarely address information needs re screening	USA
Ford, S. et al.	1995	The influence of audiotapes on patient participation in the cancer consultation	RCT	Promising practice	117 patients: 45 to tape group, 44 to control group.	Prior to the first consult, audiotape and control group patients filled out demographic, GHQ and HADS Scale. Intervention group patients received an audiotape of the consultation to listen to at home but no other instructions were given. Controls did not receive a tape or any other material. Patients then came in for a second consultation which was taped. The two consultations were analysed for questions asked and ratio of doctor/patient talk. No significant differences were found in the mean number of questions asked (across all topics) between tape and control groups either during the first or second consultation. In the second consultation, 77% of those who received a tape asked for clarification/expansion of specific details they were unsure about compared with 57% of the control group (p=0.04). 61% of control group patients requested information (all topics) regarding facts already supplied to them in their first consultation compared to 39% of tape group patients (p=0.05). There was no difference in psychological health between the two groups. The authors suggest that tapes should not be issued to patients with poor prognosis who use repressive coping techniques due to the harm that may be caused by re-exposure to distressing information. Authors argued that audiotapes do reduce the amount of requests for information previously given and increase requests for clarification of issues previously not clearly understood in an emotionally charged consultation.	audiotape effectiveness	UK
Heyn, L. et al.	2013	Effects of an interactive tailored patient assessment on patient-clinician communication in cancer care.	Comparison/control group	Acceptable practice	94 intervention patients & 99 control patients	The intervention was an interactive tailored patient assessment tool (Choice) of symptoms completed before the consultation with a summary provided to the clinician and patient vs. usual consultation practice. The consultation could be initial/ continuing/outpatient follow-up. Audiotape consultation data was analysed using standardised methods. Overall intervention subjects asked more questions particularly about symptoms and were provided with more information by clinicians. The effects are subtle, the patients were not randomly allocated to group and no analysis of data by type of consultation is provided.	Symptom checklist pre-consultation	Norway

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Holmes-Rovner, M. et al.	2007	Are Patient Decision Aids the Best Way to Improve Clinical Decision Making? Report of the IPDAS Symposium.	Overview of a debate	Expert opinion	NA	Overview concerning debate as to whether patient decision aids are the best way to improve clinical decision making (CDM). Mainly concerned with pDAs rather than QPL type interventions although these can be considered decision support interventions. Noted that communication training of physicians and/or patients have not been compared with the use of decision aids alone and identifies numerous issues for further research.	Role of pDAs in clinical decision making	USA
Irwig, L. et al	2008	Smart Health Choices	Expert Opinion	Expert Opinion	NA	Book one in a series of six 'Smart Health Choices' books, aims to help consumers and practitioners develop the skills to assess health advice – and hopefully to make decisions that will improve the quality of their care. 5 core questions and a suggested 'flow chart' for working through the questions. These are expanded on in book 2 in the series: 'Your Body Your Choice', where a set of 'sub-question' are provided: 1) What will happen if I wait and watch? 2) What are my test or treatment options? 3) What are the benefits and harms of these options? 4) How do the benefits and harms weigh up for me? 5) Do I have enough information to make a choice? It is a user friendly easy to read step by step guide for helping to make informed decisions.	Patient skills to assess health advice	Australia
Jefford, M. et al.	2011	Development and pilot testing of a nurse-led post treatment support package for bowel cancer survivors.	Pilot testing	emerging practice	10 patients	A study to develop and pilot test an innovative support care program, 'Survivor Care' for people with potentially curative colorectal cancer. QPL is a component of the educational material for the program.	This study was only a pilot test. Survivor Care, including QPL, to be evaluated by a RCT	Australia
Jevsevar, D. S.	2013	Shared decision making tool: should I take antibiotics before my dental procedure?	Outline of a shared decision making tool - dental	NA - descriptive article	NA	Outlines a shared decision making tool concerning whether antibiotics should be taken before dental procedures for patients that have previously had an orthopaedic implant. The tool includes an information booklet concerning the pros and cons of the intervention, a patient knowledge survey and a patient checklist and a patient decision.	SDM tool with QPL	USA
Katz, M. G. et al.	2007	Patient literacy and question-asking behavior during the medical encounter: a mixed-methods analysis.	Audiotape consultation analysis by literacy level	Emerging practice	57 patients - various conditions	Audio-taping and analysis of the consultation of fifty seven outpatients attending an internal medical consultation with a hospital clinic doctor. Literacy level was assessed by the REALM measure and 39% patients read at or below the 6th grade level. There was no difference in the total number of questions asked by patients with low literacy but they asked fewer questions about the key medical aspects of their care. Low literacy subjects asked the Dr to repeat information more often. The convenience sample was predominantly Afro-American limiting the generalisability of the findings.	Literacy and QA	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Lam, W. et al	2013	Does the use of shared decision-making consultation behaviours increase decision making satisfaction among Chinese women facing decision for breast cancer.	Analysis of degree of SDM in consults and pre and post treatment patient surveys	Emerging practice	283 breast cancer patients	Video recording and analysis of shared decision making (SDM) aspects of 283 diagnostic decision making consultations (e.g. lumpectomy/ mastectomy) in Hong Kong. Overall the rate of doctor SDM behaviour was low. The extent of SDM behaviour was related to longer consultation duration, more than one treatment being offered, and a lower rate of question asking by patients. It may be that patients ask more questions when the style of the consultation is low in doctor SDM behaviours or that some of these questions may concern asking the doctor to repeat what he said or clarify medical jargon - an issue that needs further clarification. Presence of more doctor SDM behaviours was associated with patient satisfaction with treatment.	Question asking in relation to SDM ratings of Drs in consultations indicated QA more common in consultations rated as low in SDM behaviours	Hong Kong, China
Little, P. et al	2001	Observational study of effect of patient centredness.	Patient surveys pre and post consultation, standardised scales	Acceptable practice	865 GP consults	The pre-consult survey probed expectations of the Dr's behaviour with regard to a patient centred approach. The post-consultation survey asked patients to rate the consultation with regard to patient centredness and the post survey also included items and scales relating to demographics, reason for consultation, anxiety and patient's enablement, satisfaction and symptom burden. The patient centredness questionnaire identified 5 components that could be measures reliably: communication and partnership, personal relationship, health promotion, a positive approach to diagnosis and prognosis and interest in the effect on the patient's life. The item concerning feeling encouraged to ask questions loaded moderately on the communication and partnership factor and this factor was a significant predictor of patient satisfaction. Patients expected a positive and patient centred approach and if this is not provided patients will be less satisfied, less enabled and may have greater symptom burden and higher rates of referral. Draws attention to the fact that question asking is only 1 component of communication and partnership behaviours.	Survey re Dr views concerning a patient centred approach	UK
Little, P et al.	2004	RCT of effect of leaflets to empower patients in primary care consultations	RCT	Acceptable practice - some design issues	636 GP patients, approx 50% intervention and 50% controls	Intervention patients received either a general information leaflet or depression leaflet or both. Both leaflets encouraged patients to ask questions during the consultation and indicated the Dr willingness to answer questions. The general leaflet was associated with a small increase in patient satisfaction which was not found for the depression leaflet. There was no significant difference in consultation time, no difference in prescribing patterns or referrals but there was a slight increase in the number of investigations. Asking questions during the consultation was not assessed. The number of subjects in each condition was unclear and data presented made the findings difficult to interrogate. Authors note that some patients may have had insufficient time to read the leaflets prior to the consultation.	Related study - leaflet encouraging QA associated but it is not a PQPL/QPL and question asking not assessed	UK

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Loh, A. et al.	2007	The effects of a shared decision making intervention.	Cluster RCT	Acceptable practice - some design issues	Intervention - physicians 20, patients 263. Controls - physicians 10, patients 142	A multifaceted intervention that included Dr training in SDM, decision board use and patient information sheet re depression which also encouraged patients to be active in the decision making process. The SDM intervention was better than usual care for improving patient participation in treatment decision-making and patient satisfaction without increasing consultation time. Patient participation was assessed by patient feedback questionnaires rather than analysis of the consultation. A post intervention follow-up concerning depression status suffered from attrition issues but indicating no difference between groups in depression severity or remission. From this study it is not possible to disentangle the effects of the various SDM components and authors suggest further research is needed to model causal linkages in the decision making process.	SDM and patient participation	Germany
McCaffery K.J., et al.	2010	The challenge of shared decision making among patients with low literacy: A framework for research and development	Literature discussion	Expert opinion	NA	Literature review re shared decision making tools and strategies for adults with low literacy. Tools need to not be so simplified that they result in a 'two-tiered' approach to decision making based on level of education. QPLs have a role in empowering patients with lower literacy to feel able to ask questions, express preferences, and to participate in health decisions. Patients with lower levels of education express less desire than more educated patients to participate in health decisions; however, increasing participation, even when it is not explicitly desired, has been associated with greater satisfaction.	Literacy, shared decision making and question asking - review	Australia
Maly, R. et al.	2004	Breast cancer treatment in older women: impact of the patient-physician interaction.	Post - treatment Survey	Acceptable practice	222 breast cancer patients	Patient post-treatment survey -independent variables were dimensions of patient -physician interaction (physician interactive informational support, physician emotional support, physician participatory decision making style and patient perceived self-efficacy) by self report. Outcome variables were patient breast cancer knowledge, treatment delay and receipt of breast conserving surgery (BCS). Used regression analyses, controlling for potentially confounding variables and found only physician interactive information support was related to the outcome variables - it predicted patient breast cancer knowledge, negatively predicted treatment delays and predicted receipt of breast conserving surgery. However, physician interactive informational support is really a measure of number of topics covered and tangible resources (e.g. leaflets) provided. Noted some racial differences in both patient knowledge and the (non) receipt of BCS in univariate vs. multivariate analyses. Suggests the provision of more comprehensive information is associated with better patient knowledge, has some broad SDM relevance but not specific to QPL.	Patient post survey concerning patient-physician interaction. Noted racial differences re knowledge and treatment disparities	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Oermann, M. H.et al.	2001	Evaluation by consumers of quality care information on the Internet.	Pilot-Study	Emerging practice	33 pilot study subjects	10 US websites, meeting Health Information Technology Institute criteria that provided information about health care quality were evaluated by the pilot study subjects. Consumers rated the health sites by answering 11 questions covering such dimensions as ease of use, whether it contained information claimed, whether they learnt anything from the website and its overall value as an information resource. The *Be Informed: Questions to ask your Dr before Surgery* was rated as the most valuable resource and the authors recommend that this plus *Prescription Medicines and You* should be made available to all patients.	Web resources evaluation	USA
Posma, E. R. et al.	2009	Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals.	Qualitative - focus groups patients and carers (2) health professionals (3)	Emerging practice	38 patients and carers in focus groups, 5 patient interviews; professional focus groups 20	Concerns older persons information needs prior to chemotherapy for cancer. Suggests older patients may require more individually tailored, but concrete and structured information; and an empathic environment to allow exploration of patient issues. Aids to enhance question asking and recall of information could also be explored.	Older person information needs	Netherlands
Sandberg E. H., et al.	2008	Clinicians constantly exceed a typical person's short-term memory during pre-operative teaching	Analysis of consultation audiotapes - preoperative anaesthesia education consults	Emerging practice	12 physician consultations; 14 nurse practitioner consultations	Analyses of these consultations were coded for 1) quantity of medical information provided, 2) frequency of medical terminology use by the provider 3) number of patient questions asked 4) number of memory reinforcements used during the consultation. Although short-term memory for pre-operative instruction is limited to roughly 7 units of content it was found that in these consultations both Dr and nurse information units far exceeded this (122 information units for nurses; 49 for Drs). This high level of information giving was not associated with the QA behaviour of patients. Authors conclude that clinicians need to be mindful of memory factors when providing information and to make more use of memory reinforcing strategies for important messages. Although not directly assessing a QPL this study suggests memory factors could potentially affect some outcomes such as knowledge recall.	Not specific to QPL alone but raises the issue of short term memory capacity in relation to communication aids that increase information provided and the potential effects on knowledge recall	USA
Shay, L.A., et. al.	2012	Factors associated with patient reports of positive physician relational communication	Pre-post study and coding of audio recorded consultations	Routine practice	485 patients, 64 physicians	This study investigates the patient, physician, and visit-related factors associated with patient ratings of positive physician relational communication. In the unadjusted, bivariate models, several patient, physician communication, and visit context factors were significantly associated with positive ratings of relational communication ($p < 0.05$). Specifically, patients with lower levels of education, those who asked more unprompted questions during the visit, who expressed physician-prompted concerns during the visit, those who interjected more unprompted assertive responses, and who reported higher levels of accumulated knowledge were more likely to rate their physician's relational communication positively. Additionally, a patient and physician interaction outside of the exam room was associated with higher ratings of physician	Patient-physician relational communication	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
						relational communication. This study offers preliminary support for the idea that relational communication and its associated benefits may be fostered through simple physician-driven acts such as interacting with patients outside of the examination room and encouraging patients to express concerns within the visit.		
Sleath, B. et al.	1999	Asking questions about medication	Thematic analysis of transcripts from patient / physician interviews	Acceptable practice	467 transcripts of patient / physician interviews	The purpose of this research was to examine physicians' and patients' question-asking about medications during medical encounters. Physicians asked patients an average of 9.3 questions about medications during each medical visit. Physicians asked significantly more questions of non-white patients, lower-income patients, and patients using more continued medications. Physicians were significantly more likely to ask questions of non-white patients ($p<0.05$), lower-income patients ($p<0.01$), and patients taking more continued medications ($p<0.001$). The results of the hierarchical linear models indicated that physicians did not perceive patients as showing more signs of irritation if they asked more medication questions ($p>0.05$) but that physicians perceived patients as showing more signs of assertiveness ($p<0.01$) and interest ($p<0.01$) if they asked more medication questions. Almost half (47%) of the patients observed did not ask any medication questions at all even though they were currently taking at least one medication; for those patients who did ask questions, the average number asked was 2.4. Starting a new medication doubled a patient's likelihood of question-asking. Physicians perceive question-asking in a positive light; patients who asked questions about medication were rated by their physicians as more interested and assertive than patients who did not ask questions, but not any more irritated or angry.	Medication and doctor and patient question asking	USA
Singh, S. et al.	2010	Shared decision making in oncology: assessing oncologist behaviour in consultations in which adjuvant therapy is considered after primary surgical treatment.	Psychometric assessment of a coding system for SDM from audiotapes and correlates of SDM	Acceptable practice	63 oncology consultations	The study involving medical and radiology consultations for patients considering adjuvant therapy developed an oncology coding system for assessing Dr SDM behaviours in audio-taped consultations and the inter-rater reliability was high (IR). The study also examined variation in SDM according to disease and patient characteristics and explored SDM in relation to patient anxiety and satisfaction (pre and post patient surveys). Noted doctor SDM behaviours seeking patient preferences were rare overall but were more apparent in female breast cancer consults and with younger patients. Patient satisfaction could not be predicted from knowledge of patient involvement preference or clinician SDM behaviours. Achievement of the preferred patient involvement was predicted by a combination of clinician SDM behaviour and patient involvement preference. No overall relationship between patient anxiety and clinician SDM scores. Relevant to SDM in general but no particular focus on QPL.	Preferred patient involvement and SDM	Canada

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Stacey, D. et al.	2012	Decision aids for people facing health treatment or screening decisions.	Systematic literature review with meta-analysis	Supported practice	86 studies	This is the recently updated Cochrane review on the effectiveness of patient decision aids for people facing health treatment or screening decisions. The review found that pDAs improved patient knowledge of options, provided more accurate expectations of benefits and harms, helped patients reach choices more consistent with their informed values and helped patients participate more in decision making. Patient decision aids were found to reduce the choice of elective surgery when patients considered other options. There are no apparent adverse effects on health outcomes or on patient satisfaction. While relevant to SDM overall the review is not relevant to the assessment of QPLs.	Review of patient decision aids	International
Stacey, D. et al.	2008	Decision making in Oncology: A review of patient decision aids to support patient participation.	Systematic literature review with meta-analysis	Supported practice	23 RCTs	Systematic review of 23 RCTs concerning patient decision aids for cancer treatment. Patients exposed to decision aids were more likely to participate in decision making, had greater knowledge recall (strong effect) and more accurate risk perceptions of treatments and were less likely to let the Dr make the treatment decision. No differences found re patient satisfaction, anxiety of health status. All pDA interventions provided information on the options, benefits and risk of treatment and implicit methods to clarify values. Simpler vs. detailed decision aids showed a smaller effect (3 studies). Discusses the cultural barriers which limit effective implementation. Refers to literature concerning effectiveness of QPL but this study did not specifically examine QPL interventions. When compared to the Kinnersley review re written communication aids it is notable that the pDAs appear to produce stronger effects concerning knowledge recall.	Review of patient decision aids	Canada
Street, R. L. et al.	2005	Patient participation in medical consultations; why are some more involved than others.	Post-hoc cross-sectional analysis of 279 consultations from 3 sites	Acceptable/ emerging practice?	279 physician-patient interactions	Examined the extent to which patient participation in medical interactions was influenced by a) patient characteristics b) physician communication style and C) clinical setting. 3 types of patients - primary care, systemic lupus and lung cancer - across 3 clinical settings. Most participation behaviours were patient-initiated rather than physician prompted. More active participants received more facilitative communication from the physician, were more educated, and were white. Female patients expressed more negative feelings and concerns. Female Drs were more likely to use supportive talk and Drs generally used less supportive talk with non-white patients. Higher educated patients asked more questions but generally the analyses considered question asking within a broader classification of active participation. Considerable variation in these findings across the settings although if not significant in one setting the data was in the same direction. Authors note that patient participation depends on a complex interaction of these factors and that racial disparities need to be further investigated.	Patient and doctor characteristics re involvement in consultations	USA
Street R.L. et al.	2008	Companion participation in cancer consultations	Audio recordings transcribed, coded and	Promising practice	48 unaccompanied patients, 84 accompanied	This study compares the communication of unaccompanied patients, accompanied patients and companions. There were no significant differences between patients with and without companions with respect to education, age, mental health status, physical health status, the number seeing the physician for	Patients and companions in consultations	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
			analysis of results		patients and 84 companions	the first time and the number seen in the oncology clinic. Patterns of companion participation varied greatly as almost half the interactions had a relatively passive companion (contributed to less than 40% of the patient plus companion active participation) but 33% of the consultations had an active companion and passive patient. Companions with less active participation accompanied black patients and received proportionally less facilitative communication from physicians. Such communicative discrepancies could contribute to racial disparities in cancer care. Patient satisfaction was lower when companion and patient had similar levels of participation. For question-asking and expressing concerns, the behaviour of companions and patients were modestly, but significantly related (r= 0.32 and r= 0.34; respectively; P<0.01). Physicians facilitated companion participation through the use of partnership-building and supportive communication.		
Tak H.J., et al.	2013	Association for patient preferences for participation in decision making with length of stay and costs amongst hospitalized patients	Patient survey linked to utilisation data	Acceptable practice	21754 admitted patients (@70%)	A survey about preferences to receive medical information and to participate in decision making was administered to all patients at a university medical center and the data was linked to administrative data on length of stay and total hospitalisation costs. 71% of patients preferred to leave medical decision making to their Dr. Patients who preferred to participate in decision making about their care had a significant but small increase in LOS and $US 865 higher total hospitalisation cost.. Preference to participate in decision making was associated with higher education and private health insurance.	Survey re patient decision making preferences in relation to cost	USA
Tattersall, M.	2002	Consultation audio-tapes: an information aid, and a quality assurance and research tool.	Literature overview	Literature overview - expert opinion	Cites 4 QPL RCTs	Discusses the usefulness to patients and family of audio-taping consultations - found useful as an information aid and to assist patient recall. Identifies that it is useful for clinical audit and as a research tool to analyse the effects of interventions -such as QPL- aimed to enhance patient and Dr communication.	Uses of audio taping	Australia
Tattersall, M. et al.	2002	Consultation audio tapes: an underused cancer patient information aid and clinical research tool.	Literature review	Literature review - expert opinion	Cites 4 QPL RCTs	Somewhat more detailed article to the one above about the usefulness to patients and family of audio-taping consultations -found useful as an information aid and to assist patient recall. Identifies that it is useful for clinical audit and as a research tool to analyse the effects of interventions -such as QPL- aimed to enhance patient and Dr communication	Use of audio taping	Australia
Tattersall, M. et al.	2002	Insights from cancer patient communication research.	Literature summary			Provides an overview re insights from cancer patient communication research. Topics raised include disclosure of information to incurable patients, and the accuracy of patient perceptions concerning their condition and treatment. Discusses the use of communications aids – audio-tapes and QPL/PQPL. Also considers patient involvement in decision making.	Patient communication research - cancer	Australia
Tiedje, K. et al.	2013	They leave at least believing they had a part in the discussion: Understanding decision aid use and patient-	Qualitative analysis of consultations and semi-structured	Emerging practice	22 patients & 19 clinician interviews; 44 video-taped consultations	The use of decision aids did not promote shared decision making behaviour in the consultations but were used as flexible artefacts which embodied patient's and clinician's existing roles in decision making. Relevant to SDM in general rather than QPL.	Patient's preferred role and the use of decision aids	International

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
		clinician decision-making through qualitative research.	interviews					
Venetis, M.K. et al.	2014	Consultation with a surgeon before breast cancer surgery: Patient question asking and satisfaction	Videotape analysis of consultation and post consultation survey	Emerging practice	51 female breast cancer patients, 1 centre	Surgical oncology context- study examines association between patient question asking behaviour during pre-surgical consultation in relation to post-consultation satisfaction with the treatment plan and the surgeon and the patient's intention to adhere to the treatment plan The frequency of patients' self initiated Qs was negatively associated with satisfaction with the treatment plan, intentions to adhere to the treatment plan and satisfaction with the surgeon. Satisfaction results may be interpreted in terms of patient perceptions that the surgeon's information was insufficient or inadequate. Begs the question as to whether increased question asking behaviour should be interpreted as a sign of consultation quality.	Question asking was negatively associated with satisfaction variables	USA
Young H. et al.	2008	Physicians Shared decision making behaviours in depression care.	A randomised trial, coding of audio-recordings	Promising practice	A total of 298 interactions between 152 physicians and 18 'standardised patients' (SP = experienced actors) were audio-recorded.	This study assesses the extent to which physicians enact SDM behaviours and describes factors associated with physicians' SDM behaviours within the context of depression care. Physicians were told that participation in the study would involve interacting with 2 unannounced simulated patients (SP) several months apart, and that each SP would present with a variety of common symptoms. Older physicians (p<0.01) and physicians who practiced in a health maintenance organization setting (p< 0.01) performed fewer SDM behaviours. Longer visit duration was associated with more SDM behaviours (p<0.01). In addition, physicians enacted more SDM behaviours with patients who made general (p <0.01) and brand-specific (p<0.01) medication requests compared with those who made no request. These results support several conclusions about the prevalence of physicians' SDM behaviour and factors affecting their use in the care of depressed patients in primary care settings. First, although health care professionals and researchers generally stress the importance of developing a clinical relationship in which patients and physicians shared decision making, most physicians in this study did not attempt to involve patients to any great extent when providing depression care. In addition, severity of depressive symptoms did not mitigate physicians' SDM behaviour because there was no difference in SDM behaviour between visits for major depression and adjustment disorder. In the context of new visits for depressive symptoms, primary care physicians performed few SDM behaviours. However, physician SDM behaviours were influenced by practice setting and patient-initiated requests for medication. One interpretation of these results is that many physicians may approach patients with a paternalistic style by default and adopt more SDM behaviours only after the patient signals interest in SDM by acting assertively.	The extent to which physicians' performed SDM behaviours in consultations with depressed patients	USA

First Author	Year	Topic	Study design	Strength of evidence	Study Nos.	Summary	Application	Country
Ziebland, S. et al.	2006	The choice is yours? How women with ovarian cancer make sense of treatment choices.	Thematic qualitative analysis of semi-structured interviews	Routine practice	43 women with ovarian cancer	Qualitative interviews were conducted in the UK with women with ovarian cancer. Interviews were audio tape recorded and transcribed for qualitative analysis. Results: Women did not always recall being involved in decisions — some felt there had been no 'real' decisions to make or said they preferred their medical team to decide on their behalf. Other women described asking questions and seeking second opinions but still 'going along with' their doctor's recommendation. A few women (including some of those who had felt unable to participate in decisions soon after their diagnosis) said that they had learnt enough to take control or make at least some of their own treatment decisions. The manner in which options were offered to women sometimes led to confusion and concern, especially if women felt the doctor was unwilling to express his or her own preference. Some worried that not accepting the doctor's advice would prejudice their future care. Patients and doctors are often uncertain how best to share in decisions about treatments. Being asked about their preferences can surprise or shock women. Clinicians need to explain about clinical uncertainty and how individual values and preferences may relate to treatment decisions. Presenting the rationale for choice can be difficult and even when well presented, women can be left feeling ill prepared, panicky and trying to second guess what they think the doctor 'really' wanted them to do.	Feedback from patients concerning the presentation of treatment choices and SDM	UK

Appendix 2: QPL Search Strategy

The review employed a rigorous search strategy to identify literature concerning the use of question prompt lists in health care.

Initially, the searches focused on the use of question prompt list or sheets in patient health consultations and in relation to shared decision making. To further inform the review, the search was broadened to include decision support aids and relevant information from the fields of physician-patient communication consumer participation and patient centred care.

Likewise, we have broadened the definition of the terms ‘question prompt list’ and ‘shared decision making’ in our search terms, given that through other literature reviews we identified terms such as ‘patient decision aids’ and ‘question asking’.

The literature searched included both Australian and International peer reviewed academic literature, alongside ‘grey literature’ such as relevant government documents and web-based information. The literature reviewed was initially limited to the years 2000 to present then expanded to include relevant earlier documents.

The University of Wollongong library resource search engine, called Summon, was initially used to search across databases such as Medline, CINAHL, Academic Research Complete, Scopus, ProQuest and other databases that UOW has access to. Summon provides access to 80% of all of UOW library resources. Further in-depth searches were then performed in the Medline and Cochrane Collaboration academic databases as suggested by Summon.

Searching techniques such as snowball searching, author searching and hand searching of reference list were also used to identify relevant literature. Search engines such as Google and Google Scholar were used facilitate these search techniques.

Searches were performed using a combination of the following terms across the above mentioned databases. The results of each search are outlined in the table below.

Table 10 Outline of Search Strategy

Search terms	Database	Result hits	Downloaded from results
"Question prompt list" OR "question prompt sheet" OR "patient prompt list" OR "patient prompt sheet"	**Summon:** used to search across 80% of UOW Library content including library catalogue and all academic databases such as Medline, CINAHL and Scopus.	208	68
Clinical decision support tools OR AND patient AND question*	Summon: results identified 291, 575 ordered by relevance, reviewed first 50 after which relevance diminished.	50	13
Patient decision aid* OR Clinical decision support tools	Summon: results identified 681, 570 ordered by relevance, reviewed first 50 after which relevance diminished.	50	17
"question prompt list" OR "question prompt sheet" OR "patient questions"	Medline	139	36
“Decision making, patient”	Medline	3,975	34

"Physician patient relations" AND "asking questions" OR question asking	Medline	106	64
"question prompt list" OR "question prompt sheet" OR "patient question list" OR "patient question sheet"	Cochrane: 8383 records		1
Hand searching of relevant systematic literature reviews	Dimoska et al. (2008); Henselmans et al.(2013); Kinnersley et al. (2007); Spiegle et al. (2013).	338	20
"Question prompt list" (results ordered by relevance and the first 100 results searched)	Google and Google advanced	52Milli on +	11
Question prompt list, question prompting, shared decision making	World Cat	72	12

List of websites and web pages searched

The following terms were used to search the following sites: Question prompt list, Question prompt sheet, Questions to ask your doctor, Questions to ask your health care provider, shared decision making.

Australian Government Departments

- Department of Health
- Cancer Australia

State and Territory Departments

- NSW Ministry of Health
- Vic Health
- Victorian Department of Human services
- Queensland Health
- WA Department of Health
- SA Health
- Department of Health and Human Services – Tasmania
- ACT Health
- NT Health

Other Australian sites

- University of Sydney, CeMPED
- Queensland University of Technology
- Cancer Institute NSW
- Peter MacCallum Cancer Centre
- Australian Commission for Safety and Quality if Healthcare
- Clinical Excellence Commission (NSW)

International sites

- Agency for Healthcare Research and Quality (AHRQ) (USA)
- National Institutes of Health (USA)
- The Netherlands Institute for Health Services Research (NIVEL)
- Ministry of Health, Welfare and Sport (Netherlands)

- Cancer.Net (American Society of Clinical Oncology)
- National Family Caregivers Association (USA)
- Centres for Disease Control and Prevention (CDC) (USA)
- ClinicalTrials.gov (USA)
- Health New England (USA)
- University of California San Francisco Medical Centre (USA)
- University of Kentucky Health Care (USA)
- Virginia Commonwealth University, Department of Social and Behavioural Health (USA)
- University of Wisconsin, School of Medicine and Public Health (USA)
- Ottawa Hospital Research Institute (Can)
- Department of Health UK
- National Health Service (UK)
- The Health Foundation (UK)