Appendix 1:

Stimulus material for focus group discussions (Abstracts of publications and title guide)

1) Treatment decision-making and its relation to the sense of coherence and the meaning of the disease in a group of patients with colorectal cancer

Purpose: The aims of the present study were to describe the preferred and the actual participating roles in treatment decision-making in relation to patients with newly diagnosed, colorectal cancer and to relate this result to the socio-demographic data, the Sense of Coherence Scale (SOC) and the patients' meaning of the disease. Eighty-six patients were studied. The following instruments were used: the Control Preferences Scale (CPS); the eight Lipowski categories of the meaning of the disease (LCMD); and the SOC. The results showed that 62% of the patients preferred a collaborative role and 28% a passive role in treatment decision-making. Agreement between the preferred and the actual participating roles was achieved by 44% of the patients. Seventy-one per cent of the patients showed an optimistic understanding of their disease. The mean SOC score was 150. There was no statistically significant difference between the CPS groups as regarded the socio-demographic data, the SOC and the LCMD. Conclusion: Socio-demographic data, the perceived meaning of the disease as well as the patients' sense of coherence were not related to the decision-making preferences in the investigated group of patients. Therefore, further investigations are needed to get an understanding of influencing factors of the decision-making preferences.

2) What do patients want? Patient preferences and surrogate decision- making in the treatment of colorectal cancer

Purpose: Clinicians often make decisions for their patients, despite evidence that suggests that correspondence between patient and clinician decision making is poor. The management of colorectal cancer presents difficult decisions because the impact of treatment on quality of life might overshadow its survival efficacy. This study investigated whether patients are able to trade survival for quality of life as a means to express their preference for treatment options and to compare their preferences with those expressed by clinicians.

Methods: Patients undergoing curative surgery for colorectal cancer were interviewed postoperatively to elicit their preferences in four hypothetical treatment scenarios. A questionnaire was mailed to all Australian colorectal surgeons and medical oncologists that asked them to respond as if they themselves were patients.

Results: One hundred patients (91 percent), 43 colorectal surgeons (77 percent), and 103 medical oncologists (50 percent) participated. In all four scenarios, patients were able to trade survival for quality of life. Patients' responses varied between scenarios, both in willingness to trade and the average amount traded. There were significant differences between patients and clinicians. Clinicians were more willing than patients to trade survival to avoid a permanent colostomy in favour of chemo radiotherapy. Patients' strongest preference was to avoid chemotherapy, more than to avoid a permanent colostomy.

Conclusions: Patients are able to trade survival as a measure of preference for quality of life and can do so differentially between treatment scenarios. Patients' preferences do not always accord with those of clinicians. Unless patients' preferences are explicitly sought and incorporated into clinical decision-making, patients may not receive the treatment that is best for them.

3) Treatment decisions for breast carcinoma: patient preferences and physician perceptions

Background: Patient autonomy and participation in treatment decision making have been encouraged in recent years. However, patients and physicians frequently disagree with regard to the patient's needs and perceptions of their illness. To the authors' knowledge, to date only limited research has assessed physicians' perceptions of patients' decision-making preferences. The purpose of the current prospective study was to determine the agreement between patient decision-making preferences and physician perceptions of those preferences.

Methods: Women with breast carcinoma who were attending their first outpatient consultation with a breast medical oncologist in a university cancer centre were enrolled in the current study. At the end of the consultation, the patients were given a survey regarding their treatment decision-making preferences that included active, shared, and passive roles in decision-making and the patients' attending physicians also were given a survey regarding their perceptions of the patients' decision-making preferences.

Results: Fifty-seven patients had complete data and were analysed. Approximately 89% of these 57 patients preferred either an active or a shared role in decision making. The agreement between patients and physicians with regard to decision-making preference only occurred in 24 cases (42%). The majority of covariates such as age, education, and income were not found to be statistically significant with regard to patient preferences or to the proportion of patients and physicians who agreed on the patient's preferences.

Conclusions: Women with breast carcinoma appear to have a strong desire for involvement in making decisions regarding their treatment. However, physicians do not appear to be consistently able to predict the decision-making preferences of their patients. Enhanced agreement between patient preferences and physician expectations mostly likely will improve communication and patient satisfaction with the treatment decision-making process.

4) Patient preference for cancer therapy: an overview of measurement approaches

Purpose: In the era of evidence-based medicine and shared decision making, the formal assessment of patient preference for treatments or treatment outcomes has attracted much attention. In this article, the two most common approaches to the evaluation of preference, i.e. utility assessment and probability trade-off assessment are described. The purpose is to provide clinicians with the background knowledge needed to interpret preference studies published in the literature and to judge whether the reported findings are relevant to their own patients.

Methods: An overview is given of the methods used to assess utilities and probability trade-off scores. Evidence on determinants of such scores is presented. Examples from oncology are provided. Because experience with the treatment plays an important role as a determinant of preferences for both treatments and treatment outcomes, special attention is paid to the interpretation of studies in the light of subject selection. Directions for future research are suggested.

Conclusion: The choice of approach and the measuring instrument depend on the goal of the preference assessment. Normal psychological processes, such as coping, adaptation, and cognitive dissonance reduction, cause patients who are about to undergo a therapy or have experienced a therapy to rate it more favourably than other patients do. This should be remembered when using evidence from the literature to inform patients or for patient decision making.

5) Lack of congruence in the ratings of patients' health status by patients and their physicians

Purpose: The purpose of this study was to examine if physician assessments of their patients' health status after the medical encounter are comparable to their patients' self-assessment of their own health.

Methods: Consecutive patients with musculoskeletal diseases were recruited when they attended 1 of the rheumatology outpatient clinics selected for the study. Five physicians participated in the study, 4 based at an academic centre and 1 in the community. Patients were interviewed after seeing the physician; they completed health status questionnaires (mHAQ and SF-12) and rated their pain, worry about disease, and overall health status on visual analog scales.

Standard gamble techniques were used to obtain patient utilities in relation to their health status, "gambling" on the probability of obtaining perfect health from an intervention with varying risks of death. After the medical encounter, physicians were asked to rate their patients' health status with similar instruments and with standard gamble elicitation techniques, blinded to the patients' responses.

Results: A total of 105 patients participated in the study; 70% were female; mean age was 54+/-16 years; 64% had a connective tissue disease, most commonly rheumatoid arthritis; and the other diseases in this group included soft tissue rheumatism, osteoarthritis, or low back pain. Statistically significant differences were observed between patient and physician ratings for pain, overall health, and standard gamble. On average, physicians rated their patients' health status higher than the patients themselves and were less willing to gamble on the risk of death versus perfect health. Intra-class correlation coefficients (ICC) were low: 0.42 for pain, 0.11 for worry, 0.11 for overall health, and 0.04 for standard gamble utilities. Similar findings were observed when subgroup analysis was performed for individual physicians and for patients with connective tissue diseases. No specific patient characteristic consistently related to increased divergence in the ratings.

Conclusions: These findings suggest that the communication between physicians and their patients at the time of the medical encounter needs to be enhanced. An understanding of their patients' health perceptions may assist physicians in suggesting appropriate interventions, taking into account their patients' benefit-risk preferences.