

CanNET

**Cancer Service Networks
National Demonstration Program**

Linking regional and metropolitan
cancer services for better
cancer outcomes



Australian Government

Cancer Australia



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**The National Assessment of
Cancer Care Perceptions
and Experiences of those
Affected by Cancer – Literature Review**

December 2008

National Assessment of Cancer Care Perceptions and Experiences of those Affected by Cancer Desktop Research



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Executive Summary

Cancer Australia has commissioned a national assessment of cancer care to determine the perceptions and experiences of people affected by cancer throughout their cancer journey (the CanNET Consumer Survey). This includes both those living with cancer, and those who care for those living with cancer. The primary objectives of the survey are to:

- Gain baseline information about the current strengths and gaps in cancer care delivery across Australia from a consumer perspective; and
- Provide information to the cancer care sector to support the development of strategies to strengthen the delivery of cancer care to the Australian community.

This report contains a review of literature pertaining to surveys and other research about people affected by cancer and the experiences of consumers in the healthcare system in general. Published research has been compiled and summarised, and the implications of this body of knowledge for the current survey are discussed. The key themes to emerge at this stage of the survey development are summarised below.

Qualitative and quantitative research approaches

The literature identifies that qualitative and quantitative methods have their own respective strengths and weaknesses but may be complementary when used together. The approach proposed in the assessment of consumers' perceptions and experiences of cancer care will draw upon both qualitative and quantitative research traditions. As part of the development of the CanNET Consumer Survey, a number of consumer focus groups, and consultations with cancer care professionals, will be conducted in the metropolitan and regional areas in which this survey will eventually be undertaken. The findings from the qualitative component of this research will not be taken in isolation but will be used to inform the development of the survey instrument. Findings from all qualitative and quantitative methods employed during the research process will be incorporated into the final project report.

Factors influencing perception

As expectations, health status and certain demographic variables play an important role in consumer perceptions of services, it is anticipated that several expectation-based questions will be included in the CanNET Consumer Survey along with items regarding health status. A number of standardised items already exist and their use may allow for comparison between surveys, though issues of copyright and proprietary materials will need to be considered. The inclusion of standardised questions such as those used by the Australian Bureau of Statistics is considered desirable.

Psychosocial bias

A number of psychosocial factors may introduce an element of bias to the CanNET Consumer Survey. These biases include social desirability response bias, ingratiation response bias, self-interest bias, cognitive consistency theory and the 'Hawthorne Effect'. While it is not possible to completely control for these types of biases, measures can be taken to minimise their effect on responses. An introductory statement will be included in the survey explaining that information gathered from the survey will be treated confidentially, and that the identity of the respondent will never be known to the researchers, the government or to healthcare providers. This statement will





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also explain that the decision to participate or not in the survey will have no effect on the services, care or treatment provided to the respondent.

Health services factors

The literature identifies a number of elements of the healthcare system as relevant to patient perceptions, such as hospital and outpatient care; primary care; the patient-practitioner relationship; and the organisation of care. All of these elements are eligible candidates for inclusion in the survey. However, during the qualitative research stage more work will be done to determine the relative importance of each of these elements to people affected by cancer so that specific questions about experience and perception can be formulated. The language used by people affected by cancer to describe these factors will be explored so that the questions devised will be meaningful and understandable to consumers.

As cancer teams are multidisciplinary, it will be valuable to firstly define the team and roles, then assess various dimensions of the consumer's relationships with different team members, and unlike many previous studies, not focus exclusively on 'the physician' or 'the nurses'.

Conceptual issues

The use of satisfaction as a measure of service quality is problematic on many fronts. The CanNET Consumer Survey is explicitly not a measure of patient satisfaction. It would appear that the most useful information will be elicited if the CanNET Consumer Survey does not depart from its stated purpose. Whilst explorations of perceptions and experiences are highly subjective, it would also be valuable to assess measures involving a greater degree of objectivity, such as experiences with waiting times at last hospital or specialist visit, and so forth.

Methodological issues

Accessing the target population

Cancer affects a range of people, including the person with cancer, their family and their community. Previous research has identified that carer ratings of health care services often differ from those given by patients. To effectively address these issues the CanNET Consumer Survey will be open to all people affected by cancer, including children, the frail aged and those receiving palliative care. In addition, carers will be surveyed. As the CanNET Consumer Survey will be designed to include *people affected by cancer*, it is proposed that a two-part questionnaire be developed with the first part relating to the patient and the second to the family or carer. The initial respondents to the questionnaire (the patient) will be asked to hand the second part of the questionnaire on to a carer or family member.

One of the major challenges facing the present CanNET Consumer Survey relates to selecting a representative sample with demographic diversity, ensuring that the sample includes a broad cross-representation of cancer types, and achieves a high response rate. One way to achieve this is to work collaboratively with a broad range of service providers and other organisations to distribute the survey to a random selection of their client base, to avoid bias. Additional questionnaires may need to be distributed to small sub-population, or sub-populations that may be less inclined to respond to the survey to enable adequate representation of these groups in the survey sample.





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These organisations are likely to include acute public and private hospitals, residential aged care facilities, hospices, in-patient palliative care units, support groups, non-government organisations and peak bodies.

The CanNET Consumer Survey may also need to specifically target certain populations such as people from Culturally and Linguistically Diverse backgrounds, young people, Aboriginal and Torres Strait Islander people(s), rural Australians and those receiving treatment in the private sector. These groups are under-represented in the existing body of research and are generally considered 'hard to reach' by researchers. Different approaches may be required to access these groups such as face-to-face interviews for Aboriginal and Torres Strait Islander people(s). These potential methods will be explored further during the qualitative research stage.

A 24 hour phonenumber will be available for people who may become distressed when completing the survey. This phonenumber will come with a toll-free number, and will be staffed by a clinical social worker who can provide support and referrals to appropriate community services.

Survey length

The review of the literature revealed that there is no established rule of thumb concerning the number of questions or length of time for interviews, but recommends pre-testing surveys during the development phase. Bias and fatigue can occur in interviews lasting more than 20 minutes.

As part of the development of the CanNET Consumer Survey, extensive cognitive testing and pilot testing will be conducted to make sure that the content and wording, and process and structure, of the survey instrument are refined prior to implementation. The challenge will be to ensure that there is a good balance between survey depth and keeping participants engaged during the testing process. A feedback form will be provided to participants as part of the pilot process that will capture information about:

- The length of time required to complete the survey;
- Any items or sections that caused uncertainty; and
- Suggested improvements to the survey instrument.

The information provided in the feedback form help to further refine the survey instrument.

At this stage, it is anticipated that the survey will on average take no longer than 20 minutes to complete and be administered using a pen-and-paper questionnaire format. It will be made clear to respondents that they may complete the survey in more than one sitting at a time that is convenient for them.

Survey content

Many surveys have been conducted in the field of service quality in cancer care, and the health sector more generally. On close examination, there is little variation in terms of the content of domains, or fields, covered in these surveys. The domains which were common to the majority of instruments reviewed as part of this desktop research are:

- Access and accessibility
- Staff competence or technical competence
- Care (which in some surveys was confined to 'medical care' or 'nursing care') and/or psycho-social support
- Continuity of care





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- Information and education, or communication
- Hotel services provided in hospitals
- Overall quality or overall satisfaction
- Outcomes.

All of these domains are considered as eligible candidates for inclusion in the survey. Each of these domains will require further exploration with people affected by cancer to assess their importance, the various elements of each domain and the language used to describe each domain.

Survey Administration

There are three main approaches to collecting survey data: in a face-to-face interview, a telephone interview, or through self-administered surveys which are often posted to respondents' homes. Advantages and disadvantages exist for each method and based on the analysis of each in addition to the requirements of the project that a pen and paper approach will be employed with strategies to boost the response rate.





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1. Background

Cancer Australia has appointed Campbell Research & Consulting (**CR&C**) to conduct the *National assessment of cancer care: perceptions and experiences of people affected by cancer* (**the project**). This project is also known by its short title 'CanNET Consumer Survey'

1.1 Cancer Australia

The national government agency, Cancer Australia works to reduce the impact of cancer on Australians. Cancer Australia works in partnership with consumers, health professionals, cancer organisations, researchers and governments. The primary aim of Cancer Australia is to improve outcomes for all people affected by cancer and particularly for those people whose survival rates or cancer experiences are poorer.

Cancer Australia has developed the Cancer Service Networks National Demonstration Program, (CanNET) to better link regional and metropolitan cancer services. CanNET will improve access to quality, clinically-effective cancer services throughout Australia, particularly for specific population groups that may currently have poorer cancer outcomes, including Aboriginal and Torres Strait Islander peoples and people living in rural and regional areas. CanNET involves the Australian, state and territory governments working collaboratively with consumers of cancer services and primary, secondary and tertiary health professionals to improve outcomes through better coordination of existing services

1.2 National Assessment of Cancer Care: Perceptions and Experiences

Cancer Australia has commissioned a national assessment of cancer care to determine the perceptions and experiences of people affected by cancer. This includes both those living with cancer, and those who care for those living with cancer. The primary objectives of the survey are to:

- Gain baseline information about the current strengths and gaps in cancer care delivery across Australia from a consumer perspective; and
- Provide information to the cancer care sector to support the development of strategies to strengthen the delivery of cancer care to the Australian community.

The *CanNET Consumer Survey* will take a central role in Cancer Australia's consumer engagement strategy.

The project has two key phases:

- Phase 1, where the feasibility and optimal approach to conducting the survey will be determined based on industry consultation and desktop research, a draft survey instrument will be designed and tested in this phase; and
- Phase 2, where the survey will be administered, collated, analysed and reported.

Whether Phase 2 proceeds will be determined by the findings from Phase 1. The decision to proceed with Phase 2 rests with Cancer Australia based on advice and input from CR&C. The design of Phase 2 (if it proceeds) will be based on the findings from Phase 1.





2. Introduction

Since the early 1980s, research investigating consumer feedback with healthcare services has burgeoned. Whilst the measurement of patient satisfaction has constituted the main focus of such evaluative activity, recent research has begun to move away from this focus and pay attention to consumers' perceptions and experiences of healthcare services.

The purpose of this desktop review is to identify effective approaches to survey design and administration from both a methodological and content standpoint. This review describes the context in which such evaluations are taking place and considers the rationale underlying contemporary research into patient satisfaction and consumer perceptions and experiences. An overview of quantitative and qualitative research methods are presented, with an emphasis on the strengths and limitations of each approach. Various factors influencing and predicting consumers' perceptions and experiences of healthcare are explored. The review also explores conceptual issues associated with the assessment of consumers' perceptions and experiences and examines some of the major methodological issues associated with research in this field, specifically: sampling, survey instruments, content areas, rating perceptions and experiences, and survey administration techniques. It also considers the implementation of research findings and identifies gaps in the literature. The implications of the findings on the development of the CanNET Consumer Survey are highlighted throughout this desktop review.

This review draws upon research largely from the social sciences and quality assurance literature. It will argue that methodologically sound assessments of consumers' perceptions and experiences can provide useful and meaningful information for health service providers and administrators to drive practice change. It will demonstrate that many of the current approaches taken to obtain feedback from consumers, specifically patient satisfaction surveys, contain flaws in their construction and execution which potentially limit their value.

Databases searched as part of this desktop research's search strategy were Medline, CINAHL, EMBASE, Meditext and PubMed. Search terms employed were: consumer(s), patient(s), perceptions, experience, journey, satisfaction, feedback, quality improvement, care, health care, cancer care, oncology, aspects, dimensions, determinant, hospital, outpatient, primary care, research, methodological, conceptual, assessment, survey, instrument, tool, questionnaire, evaluation, and review. Articles dating back from 1985 to August 2008 were reviewed as part of this research. Whilst much of the discussion will focus on the 'patient satisfaction' literature, this simply reflects the preponderance of articles on this subject matter, and the relatively small number of papers addressing consumers' perceptions and experiences.

2.1 Context

Assessments of patient satisfaction with healthcare are not a recent phenomenon. They were first developed in the United States during the 1950s, and by the 1960s began appearing in the United Kingdom (Batchelor, Owens et al. 1994). Patient satisfaction surveys initially explored the relationship between satisfaction and compliance, which as Draper and Hill (1995) noted, helped to legitimise patients' views and perceptions whilst also leading to their inclusion in quality review activities. By the 1960s and 1970s, the consumer movement asserted that patients, as healthcare consumers, had a social right to be heard, and not merely to foster patient compliance (Draper and Hill 1995).

During the 1980s, neoliberal or economic rationalist theories gained prominence among many governments, policy makers and healthcare administrators in a number of industrialised countries,





including Australia. Accompanying these market-oriented perspectives was the view that surveys to monitor patient satisfaction should be used frequently (Batchelor, Owens et al. 1994). Increasing attention was paid to concepts such as quality, outcomes, clinical indicators, total quality management, continuous quality improvement and benchmarking (Zastowny, Stratmann et al. 1995). Indeed, evaluative activities increased significantly during this period, as governments investigated more efficient and effective ways to provide services within budgetary constraints (Draper and Hill 1995). In the period between 1980 and 1996, for instance, more than 8,000 papers discussing patient and consumer satisfaction were published (Coyle and Williams 1999); (Sitzia and Wood 1997). The publication of such papers appears to have peaked between 1994 and 1995 (Sitzia and Wood 1997). Since the majority of patient satisfaction studies are not intended for publication in the scientific literature, it is likely that this figure significantly under represents the true number of surveys conducted during this period.

More recently, there has been a shift towards partnership models, and the notion that consumers and providers are co-producers of care. This perspective assumes that the power (or control) of care is shared equally between providers and consumers; both parties, therefore, have an interest in maintaining the quality of care (Draper and Hill 1995); (Stevenson, Sinfield et al. 2004). Approaches emphasising consumer participation in the planning and implementation of healthcare have also become increasingly popular. This perspective is evident in Cancer Australia and the CanNET Program's core guiding principles (add webpage reference <http://www.canceraustralia.gov.au/cannet-homepage.aspx>), which advocate consumer participation as one of three key elements to improve cancer care and outcomes (Amos, Hirst et al. 2008).

Urden has attributed the growth in assessments of consumer perceptions of healthcare and services to changing demographics, in particular ageing baby boomers with high expectations (Urden 2002). She notes that demonstrating quality outcomes and consumer satisfaction with services has assumed paramount importance for many healthcare services.

2.2 The purpose of assessing perceptions and experiences of healthcare

Monitoring consumers' perceptions and experiences of healthcare services is important for continuous quality monitoring and improvement in the provision of healthcare services. Feedback from consumers can be used by healthcare administrators to identify consumers' needs, perceptions and concerns, identify areas of service failure, and permit improvements to be evaluated as they are implemented (Crow, Gage et al. 2002). In addition, they provide organisations with an incentive to improve the quality of performance. From their systematic review of the patient satisfaction literature, Crow and colleagues remark that there is considerable evidence that satisfied consumers are more positive about their situation; they tend to be more acquiescent and cooperative and more likely to actively participate in their treatment. Conversely, disgruntled and stressed consumers whose expectations are not being met may be more hostile and resistant to treatment. Finally, in light of finite resources and the increasing costs of providing healthcare services, it is important for providers to demonstrate the cost-effectiveness of new technologies and treatments, and the practical application of evidence-based medicine (Crow, Gage et al. 2002).

As previously noted, the primary objectives of the CanNET Consumer Survey are to:

- Gain baseline information about the current strengths and gaps in cancer care delivery across Australia from a consumer perspective; and





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- Provide information to the cancer care sector to support the development of strategies to strengthen the delivery of cancer care to the Australian community.

Findings from this survey will thus be relayed to providers, administrators and decision makers. In turn, these findings will contribute to continuous quality improvement processes within cancer services in Australia.

3. Overview of methodological approaches

There are two main approaches to assessing consumers' perceptions and experiences: quantitative and qualitative methods. Whilst these methods have their own respective strengths and weaknesses, they may be complementary when used together.

3.1 Quantitative methods

Quantitative methods are concerned with the measurement of numerical data, which can be analysed using statistical methods. Consumers' perceptions and experiences are measured using standardised, pre-coded surveys. Such surveys consist of mailed self-report surveys, or interviewer-administered surveys which are completed in person or by telephone. This standardised approach ensures results can be compared and benchmarked with other service providers. The vast majority of published studies measuring patient satisfaction and consumers' perceptions and experiences have used standardised surveys.

However, the structure of surveys is generally pre-determined by researchers. As such, they may be influenced by the researchers' priorities or perceptions of what is important to consumers (Crow, Gage et al. 2002).

3.2 Qualitative methods

Qualitative methods are becoming more commonplace in healthcare research, and comprise diverse approaches including interviews with individuals, focus group discussions or observational studies. Interview-based methods may be semi-structured or in-depth. Whilst the data they generate cannot easily be reduced to numerical form, they make an important contribution to social research as they interpret data according to the subjective meanings attached to them by individuals (Pope, van Royen et al. 2002).

As interview methods are designed to elicit consumers' own perceptions and experiences, they are able to uncover issues or concerns which had not been anticipated by researchers (Pope, van Royen et al. 2002). Qualitative studies have often detected issues which have not been identified through conventional surveys. Draper and Hill, for instance, relate stories about consumers who had previously registered satisfaction in telephone surveys, but who later reported dissatisfaction with care during focus group discussions (Draper and Hill 1996).

However, qualitative approaches may lack representiveness among selected participants. Participants also lack anonymity, which may result in information being withheld due to the fear of disapproval of others (Urden 2002). They are also more labour-intensive, and hence more costly, than quantitative methods. They also require skilled researchers possessing flexibility, sensitivity and the ability to engage participants. These methods may be viewed by some as lacking scientific rigour, and hence credibility.





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Notwithstanding the various strengths and weaknesses of each approach, the use of both quantitative and qualitative methods of data collection in healthcare research is recommended to provide cross-checks and improve the overall validity of research findings (Crow, Gage et al. 2002); (Draper and Hill 1996).

Implications for the CanNET Consumer Survey

The approach proposed in the assessment of consumers' perceptions and experiences of cancer care will draw upon both qualitative and quantitative research traditions. Findings from the qualitative component of Phase 1 will not be taken in isolation; rather, they will be integrated with the quantitative results from the survey conducted in Phase 2. The survey may serve as a 'trigger' for further qualitative research, whereby issues raised in the quantitative survey can be explored in more depth using focus groups, depth interviews etc.





4. Factors influencing perceptions and experiences

The previous section has highlighted the difficulties associated with measuring patient satisfaction when the term 'satisfaction' is inadequately conceptualised. This section will review the evidence addressing the determinants of satisfaction, as one would expect these same factors to exert a similar influence over consumers' perceptions and experiences of healthcare. The framework and a significant portion of the evidence presented in the following section come from Crow and colleagues' systematic review of the patient satisfaction literature (Crow, Gage et al. 2002).

An awareness of these factors will ensure that relevant, salient aspects are incorporated into the development of the CanNET Consumer Survey instrument.

4.1 Expectations

The literature contains many references to the supposed relationship between expectations and satisfaction (see Urden 2002). However, in their systematic review, Crow and colleagues report that the evidence concerning the influence of consumers' expectations on their satisfaction levels is '*patchy, superficial and in some ways contradictory*' (Crow, Gage et al. 2002). For instance, research from the United States consistently demonstrates a positive association between satisfaction and expectations: consumers who expected high quality care reported higher levels of satisfaction and were more likely to return to the care provider than people whose expectations were lower (Crow, Gage et al. 2002). However, in the United Kingdom the causal pathway is not so clear, as satisfaction was not wholly determined by expectations being met (Crow, Gage et al. 2002).

There is evidence that expectations fluctuate depending on an individual's knowledge and prior experience, and are thus likely to be modified with accumulating experience (Sitzia and Wood 1997). This finding suggests that the CanNET Consumer Survey would need to assess not only consumers' expectations regarding their care and treatment, but their knowledge of treatment regimes (such as efficacy of treatments such as surgery, chemotherapy and radiotherapy) and past experiences with treatment (such as degree of difficulty being diagnosed, accessing treatment, effectiveness of previous treatments, views about care providers' interpersonal skills and technical competence, and so forth). Assessing consumers' expectations will thus permit the CR&C researchers to control for this variable.

Implications for the CanNET Consumer Survey

The inclusion of expectation-based questions will be considered in the development of this survey. The inclusion of questions about expectations will enable exploration of the relationship that has been suggested by other research. Further, these questions may provide the ability to control for the effects that expectation has over perception.





4.2 Health status

From their systematic review, Crow and colleagues report that there is evidence that 'poorer physical health status, disability, low quality of life, and psychological distress' are correlated with lower levels of reported satisfaction (Crow, Gage et al. 2002). Furthermore, changes in health status can influence reported levels of satisfaction for lengthy periods. For example, Crow and colleagues report that one study among (non-specified) surgical patients found that six months post-discharge, those who recounted having had the greatest absolute or relative improvements were the most satisfied (Crow, Gage et al. 2002). Consequently, Crow and colleagues recommend that researchers obtain health status data from participants being surveyed in order to gauge accurate interpretations of comparative satisfaction (Crow, Gage et al. 2002). They also suggest modelling separately the effect of health status on satisfaction during illness, as well as during the follow-up period. It will be important for the CanNET Consumer Survey to assess consumers' health status, mental health status, presence of a disability, and perceived quality of life, as these factors have all been shown to mediate satisfaction, and hence perceptions and experiences of care.

Implications for the CanNET Consumer Survey

Items regarding health status should be included in the current survey. A number of standardised items already exist including those created by CR&C, the Picker Institute and the Australian Bureau of Statistics. The use of standardised items may allow for comparison between surveys, though issues of copyright and proprietary materials will need to be considered.

In our previous work for the Department of Health and Ageing, CR&C has assessed and compiled a number of standardised questionnaire items for various Consumer Perceptions and Experiences Surveys. These may be able to be incorporated into the CanNET Consumer Survey.

4.3 Socioeconomic and demographic variables

A range of socio-economic factors need to be considered in the design of survey instruments such as the CanNET consumer survey. These include age, gender, ethnic background and socio-economic status.

4.3.1 Age

Crow et al's (2002) systematic review confirmed the widely held view that older people were significantly more satisfied than younger people in the vast majority of studies they examined. (It is worth noting that Crow and colleagues did not specify the age limits defining older people in these studies.) This finding may be attributed to older people having lower expectations of services, being more stoical and tolerant, having deferential attitudes towards care providers, or engendering more care and respect from providers compared to younger people.





4.3.2 Gender

It is generally accepted that it is not possible to draw any firm conclusions about the association between satisfaction and the respondent's gender (Hall and Dornan 1990); (Sitzia and Wood 1997). This view was supported by Crow et al's (2002) systematic review.

4.3.3 Racial, ethnic and minority groups

An association between race or ethnicity and satisfaction was documented in around half the studies investigating this variable in Crow et al's (2002) systematic review. In three-quarters of these studies, people who were black or from other visible minority groups were less satisfied with healthcare services. In the United States, there is evidence that 'white people' (sic) are largely more satisfied than 'non-white people' (sic). To date, the impact of using interpreters, or interviewing culturally and linguistically diverse groups using their first language, has not been addressed in the literature.

4.3.4 Socioeconomic status

Crow et al (2002) report that a small number of studies which investigated the effect of income on reported satisfaction found that people with higher incomes were more satisfied with doctors' interpersonal skills, whilst those with lower incomes experienced more problems as hospital inpatients. Studies from the United States where more affluent patients have reported higher satisfaction have been attributed to physicians providing 'better treatment' to wealthier people compared to those who were 'less privileged' (Sitzia and Wood 1997):1835). The impact of education level on satisfaction has been investigated by some researchers. In general, around half of such studies have reported no association between education level and satisfaction; whilst a third of these studies found that higher levels of education were associated with lower levels of satisfaction (Crow, Gage et al. 2002). Studies measuring level of education have generally focused on years of education rather than level of literacy. Nevertheless, in the majority of cases, the association between socioeconomic indicators and satisfaction were inconsistent and inconclusive (Crow, Gage et al. 2002).

It is customary for surveys to measure and aggregate all of these socioeconomic and demographic variables, despite evidence that not all factors are able to predict satisfaction, perceptions or experiences. As a consequence, these variables will be measured and aggregated as part of the CanNET Consumer Survey.

Implications for the CanNET Consumer Survey

A detailed demographic section including these variables can be included in the survey. Again, the inclusion of standardised questions such as those used by the Australian Bureau of Statistics is desirable.





4.4 Psychosocial biases

Sitzia and Wood have identified a number of psychosocial factors which may shape expressions of satisfaction and introduce bias into research (Sitzia and Wood 1997).

- *Social desirability response bias* postulates that consumers report greater satisfaction than they actually feel as they perceive that positive comments will be more acceptable to survey administrators.
- *Ingratiation response bias* takes place when respondents attempt to ingratiate themselves with researchers or medical staff when completing surveys, particularly when the respondents' anonymity may be compromised.
- *Self-interest bias* occurs when consumers believe that expressions of satisfaction will contribute to the continuation of services, from which the consumer will benefit.
- *Cognitive consistency theory* maintains that consumers are more likely to report that they are satisfied to justify the time and effort they have invested in their treatment and care.
- *The 'Hawthorne Effect'* proposes that consumers are more likely to report positive perceptions of a service due to the additional attention implicit in the data collection process and the research sponsors' apparent concern about the consumers' level of satisfaction.

It is difficult to measure the presence of psychosocial determinants in a survey, even though they may introduce significant sources of bias into research. In reality, few respondents would have a conscious awareness that their responses may be influenced by psychosocial factors, and that their responses are hence not wholly truthful. To overcome these obstacles, it will be important to communicate very clearly to the prospective CanNET Consumer Survey respondents that their responses are confidential, that their anonymity will not be compromised, that survey administrators want their responses to be truthful no matter how disparaging they may be, and that the results will be used for quality improvement purposes and not resource redistribution. In addition, assessing consumers' dissatisfaction, and asking them about negative perceptions and experiences, may help consumers to feel comfortable responding truthfully to the CanNET Consumer Survey.

Implications for the CanNET Consumer Survey

While it is not possible to completely control for these types of biases, measures can be taken to minimise their effect on responses. For example, an introductory statement can be included in the survey explaining that the survey is completely confidential, and that the identity of the respondent will never be known to the researcher, the government or to healthcare providers. The statement can also explain that participation (or not) in the survey will have no effect on the services, care or treatment provided to the respondent.





4.5 Health service factors

Numerous studies have explored various factors related to health services, specifically, satisfaction with inpatient and outpatient hospital care, primary care, the patient-practitioner relationship, and the organisation of care.

4.5.1 Hospital and outpatient care

Hospital studies consistently highlight the importance to consumers of interpersonal relationships and communication with their health care providers, as well as the care provided by staff, particularly nurses (Crow, Gage et al. 2002, Urden 2002)

Important issues to patients are general accessibility (with lengthy waiting times a universal cause of dissatisfaction) and the quality of patient-doctor communication and the information provided (Crow, Gage et al. 2002). There is evidence of higher satisfaction among consumers receiving preventive or health promotion services, whilst studies from the United Kingdom reveal that both doctors and patients alike favour longer consultations (Crow, Gage et al. 2002).

4.5.2 The patient-practitioner relationship

When evaluating care, it has been found that health care consumers attach very high importance to the nature and quality of the patient-practitioner relationship (Coyle and Williams 1999). There is evidence that physicians' interpersonal skills influence satisfaction; consumers favour a personalised, warm, friendly approach and generally prefer partnership arrangements (Crow, Gage et al. 2002). Physician feedback and discussions around treatment were also associated with satisfaction (Crow, Gage et al. 2002). No evidence of a correlation between a physician's age or gender and satisfaction was found (Crow, Gage et al. 2002).

4.5.3 The organisation of care

The majority of studies are concerned with healthcare financing in the market-maximised United States healthcare system. In Australia and the United Kingdom, the low levels of interest in methods of financing healthcare no doubt reflects the monopoly supply positions of publicly-funded Medicare services and the National Health Service in both countries. One study reported in Crow et al's (2002) systematic review noted that consumers who were members of private health insurance schemes were less satisfied with publicly-funded services than non-members. Studies from the United States which have evaluated evidence about the association between fee-for-service and pre-paid health insurance schemes has revealed that there is higher satisfaction with fee-for-service funding arrangements (Crow, Gage et al. 2002). There is speculation that satisfaction arising from fee-for-service arrangements is due to '*trust-generating behaviour by physicians that is encouraged by the nature of their remuneration arrangements*' (Crow, Gage et al. 2002):64).





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5. Conceptual issues

As previously mentioned, the consumer feedback literature is dominated by the measurement of patient satisfaction. In the following section, the conceptualisation of satisfaction in the patient satisfaction research, specifically the difficulties entailed in developing a comprehensive conceptual model of satisfaction, will be discussed. It will be argued that assessments of consumers' perceptions and experiences have a greater potential to elicit the type of feedback which in turn can lead to improved healthcare and outcomes.

It is only possible to measure patient satisfaction when a clear definition of satisfaction exists, and the determinants of satisfaction have been documented. However, various reviews of the measurement of patient satisfaction have noted that there is no agreed definition of the concept of satisfaction (Batchelor, Owens et al. 1994); (Carr-Hill 1992); (Draper and Hill 1996); (Sitzia and Wood 1997), a factor which Sitzia and Wood have described as the '*greatest single flaw in patient satisfaction research*' (Sitzia and Wood 1997), and which has hindered measurement efforts and constrained the interpretation of survey results (Crow, Gage et al. 2002).

Carr-Hill has been highly critical of the conceptualisation of satisfaction, especially the idea that satisfaction is a unitary concept. Instead, he argues that satisfaction is a '*complex concept that is related to a number of factors including life style, past experiences, future expectations and the values of both individual and society*' (1992, 237). He asserts that satisfaction with healthcare is predominantly a 'derived concept', hence it is more important for research in this field to search for sources of dissatisfaction. He also comments that satisfaction is '*likely to be defined very differently by different people and by the same person at different times*' (1992, 237):

To date, very few studies have explored the concept of dissatisfaction. Coyle and Williams (1999) attribute the lack of attention paid to dissatisfaction to the belief that it is the opposite of satisfaction, and consequently believed to already be defined. They state that this assumption is not supported by evidence from the literature. Indeed, satisfaction and dissatisfaction can exist simultaneously.

Furthermore, studies which have asked consumers to rate their satisfaction with healthcare have typically recorded very high levels of satisfaction. Batchelor et al (1994:25) report that '*studies overwhelmingly show that the majority of consumers, usually 80 per cent or more, express overall satisfaction with their care, with few respondents responding negatively to any given item*'. More recently, the New South Wales' *Cancer Patient Satisfaction Survey 2007* reported that '*more than 90 per cent of overnight cancer inpatients rated their overall care as excellent, very good or good*' (Heading, Mallock et al. 2008):3). However, commentators such as Carr-Hill (1992) believe such findings are of limited usefulness (other than for public relations purposes). Instead, he argues that health service managers need to know what is wrong, *not* what is right.

Clearly, alternative methods for eliciting consumer feedback are required. Assessing consumers' perceptions and experiences constitutes one such alternative evaluative strategy, although it was clear from the literature search strategy that this area has received comparatively little attention from researchers until recently. In this paper, **perceptions** have been defined by CR&C for the purpose of this survey as '*intuitive judgments and awareness derived through sensory stimuli*', whilst **experiences** are defined as '*the accumulation of knowledge that results from direct participation in events or activities*'. This approach attempts to overcome the problems encountered by studies measuring satisfaction, particularly when it is ill-defined.





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Another strategy involves seeking objective feedback from consumers, for example, about topics such as waiting times. Approaches which seek objective feedback can help to identify trends over time and permit comparisons between different players in the healthcare system (Carr-Hill 1992).

Implications for the CanNET Consumer Survey

As was articulated at the commencement of the project, the CanNET Consumer Survey is explicitly not a measure of patient satisfaction. It would appear that the most useful information will be elicited if the CanNET Consumer Survey does not depart from its stated purpose. Whilst explorations of perceptions and experiences are subjective, it would also be valuable to assess objective measures, such as experiences with waiting times at last hospital or specialist visit, and so forth.





6. Methodological issues

When assessing feedback from healthcare consumers, methods employed must be appropriate and scientifically rigorous to ensure that data obtained is accurate and meaningful. As Carr-Hill (1992:247) laments, *'it is depressing that people still devote very considerable amounts of valuable time and effort to types of research which cannot possibly hope to achieve their aims.'* Crow et al (2002:21) concur, stating:

'Methodological weaknesses may generate misleading results and send out erroneous signals. To the extent that feedback influences service delivery, inappropriate decisions and resource allocations may follow from poorly designed and executed data collection exercises.'

The main methodological shortcomings of studies assessing consumer feedback, including patient satisfaction surveys, will now be examined. Strategies to overcome these shortcomings will also be presented.

6.1 Sampling

Obtaining a representative sample is one of the biggest challenges facing researchers. Random sampling among the target population is most likely to yield a representative group of potential respondents. Additional questionnaires may need to be distributed to small sub-population, or sub-populations that may be less inclined to respond to the survey to enable adequate representation of these groups in the survey sample. The total sample can be subjected to weighting during analysis to correct for this over-sampling of specific populations.

Failure to obtain a representative sample leaves the research vulnerable to various sources of bias; in turn, biased results limit the generalisability of research findings.

Selection bias occurs when there is a difference between the characteristics of those selected to participate in a study and those who were not selected. It is common for researchers to have difficulty getting adequate sub-samples of some populations, notably people from culturally and linguistically diverse backgrounds (Draper and Hill 1996).

Selection bias also takes place when potential participants are excluded from participating in research. Certain groups of consumers, such as children and adolescents, people with a mental illness, those who are seriously ill and people with cognitive impairment are seldom asked to judge a service (Batchelor, Owens et al. 1994; Draper and Hill 1996; Wensing and Elwyn 2002). In addition, indirect users of healthcare services, such as consumers' families and carers, and professionals, are often overlooked in consumer feedback research. To address this oversight, Carr-Hill (1992) suggests that researchers distinguish between actual users, carers and professionals.

The minimum response rate required to ensure findings are generalisable has been estimated to be 50% (Crow, Gage et al. 2002). *Response bias* takes place when response rates to surveys are low. There is considerable evidence that the characteristics of survey respondents and non-responders differ, with non-respondents more likely to be non-white, less well educated, and in the United States, lacking health insurance (Crow, Gage et al. 2002). One simple strategy which has been found to increase the response rates of mailed surveys is the inclusion of a pen (Crow, Gage et al. 2002).





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Carr-Hill (1992) suggests that researchers sometimes employ unconventional practices, especially when calculating response rates, with variations in the ways subjects are intentionally or unintentionally excluded making it difficult to interpret response rates. It is generally accepted that the response rate should always be reported, with the numerator and denominator clearly defined. However, Carr-Hill (1992) recommends researchers go one step further, considering research in which a commentary on the characteristics of the achieved sample versus the target sample is provided, and a small sample of non-respondents is interviewed, as 'positively good practice'.

One approach to neutralizing non-response bias is stratified or quota sampling. *Stratified sampling* involves arranging a population (such as people with cancer) into separate 'strata', and then selecting a sample from each 'stratum' (for example, by cancer type). Sample sizes generally need to be in proportion to the relative size of the strata from which they are drawn. This approach ensures that there is adequate representation within a sample of consumers with less common types of cancer. *Quota sampling*, on the other hand, involves allocating the population into mutually exclusive sub-groups, and then selecting the subjects from each allocation based on a predetermined proportion. For instance, a researcher may elect to sample 50 consumers with multiple myeloma and 60 consumers with thyroid cancer. However, Crow and colleagues note that neither stratified or quota sampling have been widely employed in the research to date (Crow, Gage et al. 2002).

There is strong evidence that response rates can be boosted when researchers provide written or telephone reminders. As previously noted, the provision of a pen has been found to help to increase response rates in postal surveys. Whilst these strategies will add to the costs of surveys, they will most likely be offset by the increased response rate.

Implications for the CanNET survey

In previous CR&C research, it was revealed that ratings given by carers differ from those given by patients. For example, the evaluation of the Hospital in the Home Program revealed that carers provide lower ratings for health services overall compared with patients (KPMG 1996).

To overcome these potential sources of bias, the CanNET Consumer Survey will be open to all people affected by cancer, including children, the frail aged and those receiving palliative care. In addition, carers and professionals will both be surveyed. Challenges facing the present CanNET Consumer Survey include selecting a representative sample with demographic diversity, ensuring that the sample includes a broad cross-representation of cancer types and treatment experiences and obtaining a high response rate. CR&C proposes to work with a broad range of service providers and other organisations to distribute the survey. These organisations may include acute public and private hospitals, residential aged care facilities, hospices, in-patient palliative care units, support groups, non-government organisations and peak bodies. Additional questionnaires may need to be distributed to small sub-population, or sub-populations that may be less inclined to respond to the survey to enable adequate representation of these groups in the survey sample.





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It may be worthwhile for the CanNET Consumer Survey to incorporate written reminders, and to include a pen if the decision is made to survey consumers using a postal survey.

The CanNET Consumer Survey will be designed to include *people affected by cancer*, thus including carers, family etc. CR&C proposes that a two-part questionnaire is designed, the first part relating to the patient and the second to the family or carer. The initial respondents to the questionnaire (the patient) will be asked to hand the second part of the questionnaire on to a carer or family member.

The CanNET survey may need to specifically target certain populations such as people from Culturally and Linguistically Diverse backgrounds, young people, Aboriginal and Torres Strait Islander people(s), rural Australians and those receiving treatment in the private sector. These groups are under-represented in the existing body of research and are generally considered 'hard to reach' by researchers. Different approaches may be required to access these groups such as face-to-face interviews for Aboriginal and Torres Strait Islander people(s). These potential methods will be discussed further during the qualitative research stage.





7. Scope

A wide array of instruments has been used to measure aspects of consumers' satisfaction, needs, experiences and perceptions of healthcare services. There is wide variation among surveys in terms of their purpose, content, and length. Furthermore, as these instruments lack standardisation, it is not possible to make valid comparisons of different service providers when different instruments have been used.

In their systematic review of the measurement of satisfaction with healthcare, Crow and colleagues et al identified some forty different instruments, listed in Appendix A (Crow, Gage et al. 2002). They noted that of the studies using a multi-dimensional survey instrument to measure satisfaction, just over half used available instruments, whilst just under half the researchers developed their own surveys. Since their listing was compiled in 2002, it is possible that additional instruments have been developed since this time, although the literature search conducted as part of this desktop review failed to find any studies published since this time. In addition, since their systematic review was confined to studies measuring satisfaction, it would not have included instruments focused on assessing perceptions and experiences, although as previously mentioned, studies examining these dimensions were relatively uncommon. .

Some of the more popular available patient satisfaction surveys include the Clinical Accountability Service Planning and Evaluation (CASPE), Patient Satisfaction Scale (PSS), Patient Judgment of Hospital Quality (PJHQ), Consumer Assessment of Health Plans System (CAHPS), Patient Satisfaction with Nursing Care (PSNC), and SERVQUAL (in various guises including as a generic survey and versions adapted to health settings).

In terms of cancer care, a comprehensive review of patients' needs assessment tools was recently undertaken by Richardson and colleagues (2005). The researchers identified fifteen such patient needs assessment tools through which patients' needs for support and care can be determined. These tools cover diverse areas, including patients' symptoms and concerns, distress, supportive care needs, experiences of communication, as well as assessments of health status and referrals. Whilst some tools were specific to certain contexts, such as oncology clinics and palliative care, most tools applied to healthcare in a more general sense.

7.1 Survey length

When designing surveys, researchers need to balance the need to ask all the necessary questions without tiring respondents. Urden (2002) remarks that there is no established rule of thumb concerning the number of questions or length of time for interviews, but recommends pre-testing surveys during the development phase. She also notes that interviews lasting more than 15 minutes may cause respondent fatigue, and may lead to bias through less accurate and honest replies. In Australia, the Australian Market and Social Research Society (undated) guideline on interview length recommend that interviews in which no incentive or prize is offered do not exceed 20 minutes in average duration.





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Implications for the CanNET Consumer Survey

As part of the development of the CanNET survey, extensive cognitive testing and pilot testing will be conducted with people affected by cancer to make sure that the content and wording, and process and structure, of the survey instrument is refined prior to implementation. They will ensure that there is a good balance between survey depth and keeping participants engaged during the interview process. There may be some capacity to incorporate visual cues into certain questions in order to reinforce the content of questions.

At this stage, it is anticipated that the survey will on average take no longer than 20 minutes to complete and be administered using a pen-and-paper questionnaire format. It will be made clear to respondents that they may complete the survey in more than one sitting at a time that is convenient for them.

The timing of the survey will be confirmed during the pilot-test.

7.2 Conceptual features of survey instruments

Hall and Dornan identified four essential conceptual features of satisfaction surveys: directness, specificity, type of care and dimensionality (Hall and Dornan 1988). *Directness* refers to whether the consumer is asked to provide a satisfaction rating or whether the researcher infers levels of satisfaction. *Specificity* covers the continuum from a specific referent event (such as a specific consultation) to a general evaluation of the healthcare services. *Type of care* pertains to the type of service being evaluated, whilst *dimensionality* covers the different aspects of care addressed in the survey.

In terms of the directness of surveys, Batchelor et al (1994) urge researchers to ask consumers about their actual experiences instead of attempting to elicit judgments on quality of care and then infer assessments of quality.

With respect to specificity, there is evidence that consumers rate items with a personal referent more highly than items using a general referent, a phenomenon that has been attributed to the socially desirable response bias (Crow, Gage et al. 2002). For this reason, there is value in measuring visit-specific and general satisfaction (or perceptions and experiences arising from both fields) separately.

Two further key concepts in the assessment of consumer feedback are *validity* and *reliability*. These concepts refer to the extent to which an instrument measures what it has been designed to measure. Validity is a multi-faceted concept. Commonly encountered types of validity include *internal validity*, which refers to inductive estimates of the extent to which conclusions concerning causes of relationships are likely to be true; *external validity*, which is concerned with the degree to which (internally valid) inferences can be generalised from the study population to broader populations; and *face validity*, which refers to whether a test can be judged a good measure or not on the 'face' of the test.

Both validity and reliability are important as they ensure that findings emanating from surveys are credible. However, a survey instrument can have validity but lack reliability, and vice-versa. In his





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analysis of the validity and reliability of 195 patient satisfaction studies, Sitzia found that less than half of these studies reported some validity or reliability data (Sitzia 1999). Only a handful of studies reported on the different elements of validity *and* reliability. Furthermore, 'new' instruments demonstrated less reliability and validity than did 'old' instruments' (Sitzia 1999). These findings have implications for the development of any new survey instruments.

These findings suggest that the CanNET Consumer Survey should be structured so that consumers are asked to provide direct feedback about their experiences. The survey should assess consumers' views pertaining to a range of types of care and aspects of care. Furthermore, it should distinguish between perceptions and experiences with specific events (such as last hospital admission or last outpatients' appointment) and overall perceptions and experiences. The testing and refinement process proposed by CR&C will ensure that the survey instrument has sufficient validity and reliability.

Implications for the CanNET Consumer Survey

The CanNET survey will elicit direct feedback about consumers' actual experiences, and their views concerning care received. Attention will be paid to ensure the survey distinguishes between consumers' perceptions and experiences of general and specific events.

The project entails a rigorous schedule of pilot testing and cognitive testing. The cognitive testing will largely assess the content of the survey including the meaningfulness of individual questions to the participant. During cognitive testing, the internal and face validity of the survey will be assessed. The pilot-test will give an estimate of the external validity and reliability of the survey. Each of these considerations will be reported to Cancer Australia at the conclusion of the development and testing stage of the project.





8. Content of surveys

The previous section has highlighted the vast number of survey instruments available to measure consumers' satisfaction with, and perceptions and experiences of, healthcare services. These instruments apply to hospital care, or ambulatory care, and can include both types of care services.

On close examination, there is little variation in terms of the content of domains, or fields, covered in these surveys. The general domains which were common to the majority of instruments reviewed as part of this desktop research are:

- Access and accessibility
- Staff competence or technical competence
- Care (which in some surveys was confined to 'medical care' or 'nursing care') and/or psycho-social support
- Continuity of care
- Information and education, or communication
- Hotel services provided in hospitals
- Overall quality or overall satisfaction
- Outcomes.

General domains which were incorporated into some, but not all surveys, include:

- Expectations and prior experience
- Satisfaction with expectations met
- Most liked and most disliked aspect
- Likely to recommend service
- Health status, including self-care, mobility, physical activity, appetite and sleep
- Respect for patient preferences
- Cost and finances
- Efficiency
- Visiting arrangements
- Patient safety or psychological safety
- Reception
- Waiting times
- Ward timetable
- Family and friends, or carers
- Discharge or transition.

Previous research has noted that specific domains have not been well represented in either generic or cancer-specific survey instruments. These domains include pain, fatigue and depression. Other neglected domains, with particular relevance to cancer, include side effects of treatment, survivorship, palliative and end of life care (Malin, Ko et al. 2006).

Likewise, there is evidence that certain domains which are not deemed particularly important by consumers dominate survey instruments. For instance, the instruments reviewed as part of this desktop research suggest that many researchers are preoccupied with 'hotel services' such as





cleanliness of facilities and quality of meals; this is despite the fact that consumers do not generally consider these aspects critical to improving outcomes (Draper and Hill 1996). These factors are likely to be included in the survey, however not as a central or core set of questions. When measuring consumers' perceptions and experiences, it is more valuable to assess domains which consumers themselves have identified as being of importance.

In terms of the CanNET Consumer Survey, these findings highlight the importance of consulting with consumers about their journey, experiences and perceptions, and incorporating these findings into the survey instrument.

Implications for the CanNET Consumer Survey

During the development of the CanNET Consumer Survey, consumers will be consulted regarding their journey, perceptions and experiences to ensure that aspects deemed important to consumers are incorporated into the survey.

One example of a comprehensive and methodologically rigorous study in which consumers with cancer's experiences and outcomes were assessed is the Cancer Care Outcomes Research and Surveillance (CanCORS) study (Malin, Ko et al. 2006). The aim of this population-based study of newly diagnosed consumers with lung and colorectal cancer was to obtain information concerning personal characteristics, decision making, processes of care (such as types of therapies received), experiences of care, and outcomes (related to symptoms, quality of life, and so forth). The survey was administered to consumers four months after their cancer diagnosis. In order to foster comparability between the CanCORS data and other studies, the researchers drew from numerous existing, validated items and scales. The sources of these items and scales are listed in Table 1.

Survey instrument	Domains or content areas
California Health Interview Survey	Demographic characteristics and insurance coverage
State of Michigan Study	Demographic characteristics and insurance coverage
Los Angeles Women's Health Care Study Baseline Survey	Symptoms leading to cancer diagnosis, decision making regarding initial treatments, participation in clinical trials, supportive care and symptom management, and provider identification
Harris poll, sponsored by the Coalition of National Cancer Cooperative Groups	Beliefs about clinical trials
Medical Outcomes Study 12 item short form (SF-12)	Quality of life
European Organisation for Research and Treatment of cancer (EORTC) QLQ C30	Description of symptoms





Table 1: Cancer Care Outcomes Research and Surveillance	
Survey instrument	Domains or content areas
EORTC Lung and Colon quality of life modular questionnaires	Description of symptoms
Centre for Epidemiologic Studies Depression Scale 8-item short form (CESD-8)	Description of symptoms
Brief Pain Inventory	Description of symptoms
MOS 36-item short form (SF-36) vitality scale	Description of symptoms
1999-2002 National Health and Nutrition Examination Survey (NHANES)	Information regarding co-morbid conditions
Prostate Cancer Outcomes Study (PCOS) Patient Survey	Information regarding co-morbid conditions
Charlson Index (patient self-report version)	Information regarding co-morbid conditions
Coronary Artery Risk Development in Young Adults study	Patients' health behaviours including smoking
National Cancer Institute Diet History Questionnaire	Use of vitamins
Consumer Assessment of Health Plans Study (CAHPS) adult core survey	Experiences of care
Picker Institute (survey of cancer patients)	Experiences of care
Northern California Colorectal Cancer Study Patient Survey	Experiences of care
Assessment of Patients' Experience of cancer care study survey	Experiences of care
Control Preferences Scale	Patients' actual and preferred role in decision making regarding cancer treatment

(Adapted from Malin et al, 2006, 839)

In addition, Malin and colleagues developed new items to ascertain whether conditions which could have resulted from complications of treatment (such as renal failure) were present prior to the cancer diagnosis, and prior beliefs regarding the efficacy and toxicity of various cancer therapy modalities (Malin, Ko et al. 2006). This survey was administered through computer-assisted telephone interviewing (CATI) technology, as completion of the survey is then not dependent upon literacy. The researchers note that the median time taken to complete this survey was 75 minutes for patients with lung cancer and 82 minutes for patients with colorectal cancer.

This CanCORS study appears to have captured all salient aspects of a consumer's journey through the cancer care system. This study may provide a basis upon which to develop the domains which will be used in the CanNET Consumer Survey. However, as noted in section 7, the length of time taken to complete this survey grossly exceeds the Australian Market and Social Research Society's (undated) length of interview guideline.





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Implications for the CanNET Consumer Survey

As discussed previously: All the general domains and content areas identified by previous surveys are considered to be eligible candidates for inclusion in the survey. Each of these content areas will require further exploration with people affected by cancer to assess the relative importance of each domain, the component elements of each domain and the language used to describe each domain.

8.1 Rating consumer perceptions and experiences

8.1.1 Scaling techniques

Pre-coded surveys are structured around stems, which measure various domains of care (such as quality of relationships with health professionals) and a scale which provides respondents with a range of options (such as strongly agree to strongly disagree). Consumers' experiences, perceptions and degree of satisfaction can thus be inferred from ratings assigned to surveys. However, standard rating scales may lack sensitivity, as the only responses permitted are those previously defined by the researcher (Batchelor, Owens et al. 1994).

A number of different scaling techniques can be used. In their simplest form, surveys may consist of 'yes-no' responses. There is evidence that such close-ended questions may lead to over-estimates of satisfaction (Batchelor, Owens et al. 1994). One scale which has been widely used is the 'excellent-good-fair-poor' scale. Whilst proponents argue that the bias inherent in this type of scale is true, it has equally been criticised by some commentators for failing to provide respondents with an opportunity to rate services from positive to negative, as indeed only one of these options is a negative response (Urden 2002). A more balanced verbal frequency scale would provide an even number of positive and negative responses, such as 'strongly agree-agree-neither agree nor disagree-disagree-strongly disagree' (Urden 2002). This format enables responses to be readily translated into numerical values.

Another commonly used scale is the Likert scale, where respondents are asked to rate aspects of a service according to a range of numerical values, for instance, on a scale of 1 to 5. The employment of Likert scales to measure attitudes has been found to generate more valid data than through the use of single measures (Batchelor, Owens et al. 1994). There is evidence that 5 point Likert scales yield greater response variability than 6 point scales (Crow, Gage et al. 2002).

To promote the validity of consumers' responses in structured, quantitative surveys, the inclusion of open-ended questions is strongly recommended (Batchelor, Owens et al. 1994).

In previous surveys, CR&C has used an indexed approach to derive an overall measure of perception. Using this approach, individual questions can be combined into a multi-item index of care by summing together the scores on each item and transforming scale scores linearly to range from 0 to 100. This approach may yield a more valid measure of overall perception and rating.





This approach was incorporated into the Victorian Patient Satisfaction Monitor (UltraFeedback undated).

These findings suggest the CanNET Consumer Survey incorporate a range of scaling techniques, such as the 'excellent-good-fair-poor' scale and Likert scales, and open-ended questions to elicit qualitative data.

8.1.2 Structure and phrasing of questions

The way in which questions are structured and phrased may adversely influence consumers' responses, and hence lessen the reliability and validity of a survey's findings.

Surveys measuring patient satisfaction commonly employ *hybrid questions*, which assess perceptions and values simultaneously. A typical example is 'how satisfied were you with the doctor/nurse, etc?', with responses ranging from 'very satisfied' to 'not at all'. Kravitz remarks that to respond to such a question, '*patients must first estimate the amount of time they spent with the doctor, compare it with an internal standard, and then provide an overall judgment.*' (Kravitz 1998) He notes that whilst hybrid questions are linguistically economical, they make it hard for patients to separate between their own perceptions and values, and to thus provide a valid assessment of their level of satisfaction. For instance, a consumer who receives poor care but who has low expectations may report the same satisfaction as a consumer who receives good quality care but who has unreasonably high standards (Kravitz 1998). To overcome these flaws in surveys, Kravitz (1998) recommends separating patient perceptions from patient values, and developing questions which target potentially mutable behaviours. It is equally important to separate consumers' experiences from their values when designing survey instruments.

In a similar vein, positively biased questions, such as 'in general, were you fairly satisfied with ...?' can lead to *acquiescent response set*, the tendency of respondents to agree with statements regardless of their actual content (Crow, Gage et al. 2002). In other words, reported satisfaction may be nothing more than acquiescence. Respondents may give illogical answers, agreeing with a pair of statements even when the content is identical but the direction of the statement is reversed (Crow, Gage et al. 2002). Acquiescent response set can be neutralised by ensuring that equal numbers of favourably and unfavourably phrased items are used (Crow, Gage et al. 2002).

In contrast, survey instruments developed by the Picker Institute have adopted an entirely different approach to measuring patient satisfaction. Consumers are not asked about 'satisfaction with communication'; rather, they are asked specific 'yes-no' questions, such as 'did the provider explain what to do if problems or symptoms continued, got worse, or came back?' (Kravitz 1998):280). Whilst data collected may lack the response variability associated with verbal frequency or numerical scales, this is compensated for by findings which are highly interpretable. Kravitz, a physician, remarks:

'If I were told that my patients' adjusted satisfaction score was a full standard deviation below the mean for all practitioners at my clinic, I'd be upset, but I wouldn't know what to do about it, and I probably wouldn't change how I practiced. On the other hand, if I learnt that 40% of my patients didn't know what to do if their symptoms returned, I might give my approach to providing follow-up instructions some scrutiny (Kravitz 1998).'

The *New South Wales Cancer Patient Satisfaction Survey 2007* (Heading, Mallock et al. 2008) is based on this Picker Institute approach to measuring satisfaction. However Picker surveys are not without their limitations, as they may still overestimate consumers' actual satisfaction with services.





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Furthermore, whether a question is open or closed-ended has been found to influence findings, as open-ended questions typically generate more negative ratings and comments than closed-ended questions (Draper and Hill 1996). This finding highlights the importance of using both quantitative and qualitative methods when conducting assessments of consumers' perceptions and experiences of healthcare services.

8.1.3 Question sequencing

The order of questions within a survey may affect overall results. It is customary for surveys to commence with general questions before shifting to specific ones. More sensitive questions, such as those measuring respondents' socio-economic and demographic status, are generally presented towards the end of the survey (Crow, Gage et al. 2002).

DeMoranville and colleagues investigated the effect of three question orders on measurements of SERVQUAL (a service quality measurement instrument) and global quality to identify which order produced the most predictive measures (DeMoranville, Bienstock et al. 2008). They randomly distributed three forms of a survey to 571 users of banking, dental services and hair salons. One survey contained specific questions, followed by general ones, then questions asking whether the user would purchase the service again. The second survey featured general, then specific, then repurchase intentions, whilst question order in the third survey was random.

The researchers found that in regard to predictive accuracy, the optimal survey format is one in which global items are presented first, followed by specific items. However, if administrators wish to diagnose global service quality constructs, the random ordering in surveys was found to be preferable as the association between global service quality and intentions for future interactions was significantly higher using random ordered questions (DeMoranville, Bienstock et al. 2008).

Randomly ordered surveys are not feasible for the CanNET Consumer Survey given the increased costs of randomisation associated with the printing of questionnaires and data entry. As the CanNET Consumer Survey is ultimately concerned with improving the quality of cancer care services, it would be worthwhile adopting a format in which global items are presented prior to specific items.

Implications for the CanNET Consumer Survey

CR&C has used a variety of scales in our research and is familiar with the application, advantages and disadvantages of each. At this stage, the *Excellent, Very Good, Good, Fair, Poor* scale that is typically employed in service evaluations would seem to be applicable to perception questions for the CanNET Consumer Survey. This negatively weighted scale is used as it provides good differentiation between positive and negative responses and can offset positivity biases inherent to service ratings.

The simple *Yes, No*, structure described above seems applicable to the experiences questions. The appropriate scale for each question will be cognitively tested with people affected by cancer.

The experience/perception structure that has been specified for the CanNET Consumer Survey largely avoids the disadvantages of hybrid questions. Using this structure, experience is assessed independently from perception.





The majority of questions will focus on specific events, (e.g., the last time treatment was received) rather than global assessments of the cancer care system.

The questionnaire will contain both open and closed ended questions to capture a broad range of information from people affected by cancer.

The questionnaire can be designed using a top-down structure moving from general questions to specific questions.

8.2 Survey administration techniques

8.2.1 Survey data collection method

There are three main approaches to collecting survey data: in a face-to-face interview, a telephone interview, or through self-administered surveys which are often posted to respondents' homes. More recently, researchers have begun distributing surveys via email. Each method has its own advantages and disadvantages (Table 2).

Method	Advantages	Disadvantages
Face-to-face interview	Most intensive approach, can produce most in-depth data Surveys people who are unable to complete self-completion surveys	Expensive Possibility of interviewer bias May not be anonymous
Telephone interview	Respondents may be more frank and less inhibited due to greater anonymity compared to face-to-face method Surveys people who are unable to complete self-completion surveys	Not possible to use visual aids Possible selection bias as respondents must have access to a telephone Possibility of interviewer bias Higher costs due to human resources required, survey inter-rater training and number of times to contact respondents
Mail self-completion	No interviewer bias Relatively cheap Respondents likely to be frank and uninhibited in responses due to complete anonymity	Possibility of low response rates and non-response bias People with poor literacy skills disadvantaged Not possible to control circumstances in which survey completed.
Email self-completion	No interviewer bias Very cheap Respondents likely to be frank and uninhibited in responses due to complete anonymity	Possibility of low response rates and non-response bias People with poor literacy skills and disadvantaged People who lack email access disadvantaged Not possible to control circumstances in which survey completed.





(Adapted from Crow et al, 2002:22; Urden, 2002:197)

Different data collection methods may produce different response rates and variations in responding. There is evidence that response rates are significantly higher (by up to 30%) for both face-to-face and telephone interview methods compared to mail surveys (Crow, Gage et al. 2002). In their analysis of the response rate in 210 published patient satisfaction studies, Sitzia and Wood (1998) found the average response rate for interview studies was 77%, compared with 67% for mail surveys. However, strategies such as the inclusion of postage-paid return envelopes, postcard reminders one week later, or telephone follow-up of mail non-respondents, may translate to an increased response rate for mailed surveys (Urden 2002; Wensing and Elwyn 2002).

Survey costing data has shown that interview methods are more costly as they are more labour intensive. In contrast, mail and email surveys are a less expensive method, except when telephone follow-up to increase the response rate is used. Crow and colleagues' conclude that: *'investigators must determine whether 'deluxe' approaches yield sufficiently superior information to merit the extra costs they incur. On the other hand, attempts to save money by cutting corners may be a false economy if they compromise methodological rigour'* (2002:32).

It is commonly believed that data should be obtained as close to the service encounter as possible, with most sources recommending a time frame of 1 to 4 weeks (Urden 2002; Wensing and Elwyn 2002). However, Crow and colleagues' (2002) systematic review of the patient satisfaction literature yielded insecure and contradictory findings on the effect of timing on consumers' evaluations of healthcare. Instead, they suggest that health status may be an important mediating factor.

Implications for the CanNET survey

Administering the CanNET Consumer Survey using interviewers (face-to-face or on the telephone) may not be possible given privacy and logistical constraints. Thus a pen-and-paper approach is proposed.

This approach has a number of disadvantages that will need to be acknowledged, primarily the limited control that the researcher has over the sample. However, this disadvantage may be outweighed by the cost effectiveness, anonymity and lack of interviewer bias of the approach.

The use of reminder letters could be considered to boost response rates. However, the additional cost and administrative burden on cancer care providers will also need to be considered.

As discussed previously: different approaches for specific populations may be required (Aboriginal and Torres Straight Islander peoples, people from Culturally and Linguistically Diverse backgrounds etc). The use of translated questionnaires can also be considered, though again, the cost of translation may limit the feasibility of this approach.





9. Gaps in the literature

The most comprehensive identification of gaps in the consumer feedback mechanisms literature comes from Crow and colleagues' systematic review of the measurement of satisfaction with healthcare (Crow, Gage et al. 2002). Their findings are summarised below.

There is a need for the effects of satisfaction on health behaviours and health outcomes to be reviewed. This will help to make providers and consumers more aware of the importance of services promoting and maximising satisfaction.

In terms of methodological issues, research in the following areas is warranted:

- Survey timing and its effect on reported satisfaction
- The extent of interviewer bias
- Cross-cultural issues
- The incorporation of consumer feedback into healthcare decision making, including consumers' preferences.

There has been a general lack of research into consumers' expectations (Batchelor, Owens et al. 1994). In regard to the role played by expectations, research in the following areas is warranted:

- The classification of different types of expectations, and exploration of ways in which consumers operationalise these in evaluations
- The identification of influences on expectations
- The association between sociodemographic variables and expectations.

Research is needed to explore how the impact and extent of consumers' illness and health outcomes affects their evaluations of healthcare.

There is a need to investigate the impact of different incentive structures on physician behaviour and patient satisfaction.

In addition to Crow and colleagues' work, two further gaps in the literature stand out. Firstly, there is a need for more research into consumers' perceptions and experiences; for too long, the emphasis has been on measuring their levels of satisfaction. As findings from such research have frequently lacked value and meaningfulness, this has made the task of translating them into service improvements a difficult one. And finally, there is a need for more intervention studies in this area, as the vast majority of studies reported in the literature are one-offs. Carr-Hill (1992) recommends that studies employ a randomised control trial research design, in which participants are randomly assigned to a control or intervention group. This study design is considered the 'gold standard' in research as it minimises many of the sources of bias which beset conventional studies. Studies which also report the process of implementing findings, the barriers and enablers encountered, and which measure whether service improvements have proved sustainable, are warranted.





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10. Implementation of research findings

This desktop review has demonstrated that consumer feedback mechanisms, in particular ones purporting to measure patient satisfaction, have flourished since the 1980s. This begs the question: has the information gathered been used to implement improvements in the quality of healthcare services?

Writing at the end of the 20th century, when the measurement of satisfaction was at its zenith, Draper and Hill reported that there was no evidence that measurement activities had led to improved care (Draper and Hill 1996). To illustrate their argument, they point to one Australian hospital quality management process which took place around this time. They state that hospital administrators were reluctant to act on the findings from one-off studies alone. Furthermore, respondents who participated in such quality management processes were frequently too powerless to influence some of the organisational and resource implications emanating from survey findings. It is likely that these barriers to change would be equally applicable to many other such quality improvement activities. Indeed, single satisfaction surveys will be hard-pressed to lead to quality improvement. Instead, they must be integrated into quality improvement cycles with at least three years of regular reviews before impacts can be realised.

Despite the many conceptual and methodological issues encountered in the consumer feedback literature, there are still valid reasons for services to assess consumers' perceptions and experiences, and to ensure this feedback translates to tangible improvements in service quality. Carr-Hill (1992) argues that measurements of patient satisfaction will be most useful when they are sensitive to changes in quality. Feedback mechanisms which focus on assessing consumers' perceptions and experiences, and which explore why certain groups of consumers are dissatisfied, will yield the most valuable information. In turn, the failure of healthcare providers to act upon the feedback they receive may result in much scepticism and cynicism among consumers (and indeed some healthcare staff), who will be wary of participating in future quality improvement initiatives.

This desktop review has highlighted both good and poor practices with respect to consumer feedback mechanisms. As previously noted, the purpose of the present CanNET Consumer Survey is to gain baseline information related to current strengths and gaps in cancer care delivery, and to provide the cancer care sector with feedback to strengthen the delivery of cancer care to the Australian community. Its purpose is *not* to measure satisfaction with healthcare services. Findings from this desktop review can be used to guide the development of the CanNET Consumer Survey tool to ensure it is conceptually and methodologically sound, and will produce findings which can be readily implemented across the cancer care sector.

Implications for the CanNET Consumer Survey

While the conduct of Randomised Control Trials is desirable, such approaches are not directly relevant to the CanNET Consumer Survey as the cancer care sector as a whole is under examination, and not a specific intervention. However, as described above, researchers conducting Randomised Control Trials in the future may wish to consider the use of the CanNET Consumer Survey as a tool to measure the impact of interventions.





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To be meaningful and useful, the results of the CanNET Consumer Survey will be made known to professionals to enable quality improvement. However, these professionals must have the ability and desire to affect meaningful change within the cancer care sector. The results of the survey can be used by policy-makers, senior hospital administration and advocacy groups within the sector.

11. Conclusion

Cancer Australia has indicated the intention to release the CanNET Consumer Survey instrument into the public domain for free use. The availability of a recognised, tested and broadly applicable survey instrument may be of great benefit to the sector. The instrument may be used by a number of different organisations such as state health departments, public and private hospitals, non-government organisations etc, thus providing some consistency across the sector.

To be meaningful and useful, the results of the CanNET Consumer Survey will be made known to professionals and consumers to enable quality improvement. However, health professionals must have the ability and desire to affect meaningful change within the cancer care sector. The results of the survey can in turn be used by policy-makers, senior hospital administration and advocacy groups within the sector.





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13. Appendix A

13.1 Satisfaction Instruments

The satisfaction instruments that have been identified have been adapted from Crow et al's (2002) systematic review of the measurement of satisfaction with healthcare literature. Where three or more authors are listed, reference is to first author's name only. Where two or more studies are associated with an instrument, only first listed study according to Crow et al's (2002) listing is shown.

UK

- Primary Care Consultations (Feletti et al, 1986)
- Surgery Satisfaction Questionnaire (SSQ) (Baker, 1991)
- Consultation Satisfaction Questionnaire (CSQ) (Baker, 1990)
- Critical Incident Technique (CIT) (Pryce Jones, 1993)
- General Practitioner Services (Grogan et al, 1995)
- Satisfaction with General Practitioners (Leavey and Wilson, 1993)
- General Practice Assessment Survey (GPAS) (National Primary Care Research and Development Centre, University of Manchester)
- Inpatient Care: University of Manchester Institute of Science and Technology (UMIST) instrument (Moore and Thompson, 1986)
- Inpatient and Outpatient Care: Clinical Accountability Service Planning and Evaluation (CASPE) system (Gritzner, 1993)
- Hospital Inpatient Survey (Bruster et al, 1994)
- Newcastle Satisfaction with Nursing Care Scale (NSNS) (Thomas et al, 1995)
- Department of Health Patient Experience Survey (Airey et al, 1998)

USA

- Satisfaction with Physician and Medical Care (Rogmann et al, 1979)
- Patient Satisfaction with Medical Care (attitude to physician, cost, convenience), evolving over a decade to Patient Satisfaction Scale (PSS) (Hulka et al, 1970)
- Patient Satisfaction Questionnaire (PSQ-I, PSQ-II) – general satisfaction with medical care from doctor (Ware et al, 1983)
- Visit Specific Questionnaire (VSQ-9) – satisfaction with office visit (Rubin et al, 1993)
- Visit Specific Questionnaire (VSQ-9) – satisfaction with ambulatory settings (Osterweis and Howell, 1979)
- Visit Specific Questionnaire (VSQ-9) – satisfaction with family practice (Di Tomasso and Willard, 1991)
- Primary Care Assessment Scale (PCAS) – quality of health plan and doctor (www.outcomes-trust.org/instruments/catalog.html)





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- American Board of Internal Medicine Patient Satisfaction project (Joos et al, 1993)
- Medical Interview Satisfaction Scale (MISS) (Wolf et al, 1978)
- Patient-Doctor Interaction Scale (Bowman et al, 1992)
- HMO Disenrollment (Weiss and Senf, 1990)
- Older Patients Satisfaction Scale (OPSS) (Cryns et al, 1989)
- Patient Judgment of Hospital Quality (PJHQ) (Picker-Commonwealth Fund project, undated)
- Inpatient Hospital Care (Press and Ganey, 1990)
- Picker/Group Hospitals Association of America – inpatient care – evolved to Consumer Assessment of Health Plans System (CAHPS) (Cleary et al, 1993)
- External Patient Satisfaction Survey (EPSS) (Dufrene, 2000)
- SERVQUAL: A generic measure of consumers' perceptions of service quality (Parasuraman et al, 1988)
- SERVQUAL: Adapted to healthcare in general (Bowers et al, 1994)
- SERVQUAL: Adapted to hospital services (Babakus and Mangold, 1992)
- SERVQUAL: Adapted to nursing (Scardina, 1994)
- Patient Satisfaction with Nursing Care (PSNC): Primary setting (Ventura et al, 1982)
- Patient Satisfaction with Nursing Care (PSNC): Adapted to hospitals (Jacox et al, 1997)
- La Monica-Oberst patient Satisfaction Scale (LMOPSS) (Munro et al, 1994)
- Patient Satisfaction with Nursing Care in Inpatient and Ambulatory Settings (Ketefian et al, 1997)
- Patient Satisfaction with Nursing Care: a Magnitude Estimation Approach – in hospital (Eriksen, 1998)
- Patient Satisfaction Questionnaire (PSQ) to assess the quality of non-physician encounters (Guzman et al, 1988)
- Satisfaction with Decisions Scale (Holmes-Rovner, 1996)

Other countries

- In Hospital – Spain (Garcia et al, 1995)
- Primary Care – Israel (Linder-Pelz et al, 1983)
- Hospital Quality Improvement – Sweden (Arnetz and Arnetz, 1996)
- In Hospital – Australia (Steven, 1991)
- General Practice – Australia (Steven and Douglas, 1986)

