

VICTORIAN PATIENT EXPERIENCE
SURVEY DEVELOPMENT PROJECT:
REVIEW OF LITERATURE RELATING
TO SURVEY TOOLS USED TO ASSESS
CANCER PATIENTS' EXPERIENCES
OF CARE

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BACKGROUND

A cancer diagnosis, places considerable stress on patients and their families. They find themselves in an unfamiliar health system; making decisions with serious and potentially long-term consequences; living with uncertainty about the nature, course and prognosis of the disease; living with a disrupted family, work and social life and facing the possibility of becoming increasingly dependent on others or if a family member the need to provide care to a loved one (CANNET surveys). Many patients experience high levels of psychological distress affecting between 30% to 43%.¹

The Victorian Cancer Action Plan (VCAP) has identified as a priority the need to create better experiences for cancer patients and their carers. To this end, the Patient Management Frameworks have orientated the health system to the delivery of patient-centred care-an orientation that views the patient as active participants in their care with their values, beliefs and preferences informing the delivery of care.^{2,3} VCAP acknowledges that quality cancer care includes the delivery of both anti-cancer therapy and supportive care to patients and their families.

The Cancer Strategy and Development (CSD) section of the Victorian Department of Health is investigating the possibility of conducting a consumer experience survey to help evaluate cancer services and a range of VCAP priorities. The CSD intends for the cancer consumer survey to inform progress of policy implementation in the areas of: i) Multidisciplinary care, ii) Care coordination, iii) Supportive care and iv) Reducing variation.

Currently, a small number of patient surveys are in regular use in Victoria. None have been designed to assess the specific issues of care relevant to people with cancer. The Victorian Patient Safety Monitor (VPSM) monitors adult patients' satisfaction with the care and services received from the State's public acute and sub-acute hospitals. As the VPSM includes all disease types it is limited in its ability to capture cancer specific satisfaction or experience. Palliative Care Victoria has implemented the Victorian Palliative Care Satisfaction Instrument in 2010 to capture patient and carer satisfaction and experience of palliative care services in the acute and community setting. While people with cancer and their carers will participate in this study, its focus on palliative care means that the experiences of curative care cancer patients are not assessed. The CSD intends that a survey of the care experiences of cancer patients will compliment and not duplicate these two surveys.

It has been suggested that quality of care assessments include three components that contribute to the total cancer experience: 1) patient perceptions of care, 2) prevalence of unmet supportive care needs and 3) health-related quality of life.⁴

'Patient perception of care' encompasses both patient satisfaction and their experience of care.⁵ Satisfaction is a subjective, evaluative assessment that is derived from expectations, needs, past experiences, opinions and attitudes.⁵ In the past, quality of care assessments has focused on patient satisfaction. However although patient satisfaction has been widely studied, its usefulness has been questioned on several grounds. First, there is concern that assessing whether care was satisfactory or adequate is incongruent with a health organisation's goal to provide excellent patient care.⁵ Second, there is concern over the correspondence between satisfaction assessments and other quality indicators with for example, one study reporting that although more than 90% of patients were very satisfied with the medical care they received, a third reported difficulties in discussing problems with their clinician and felt their clinician did not spend enough time with them.⁶ Third, other work has identified systematic biases in satisfaction assessments, with older patients generally found to be more satisfied than younger patients; and lower socioeconomic status (SES) patients generally more satisfied than higher SES patients.⁷ In addition, more recently there has been recognition that satisfaction is a multidimensional construct with patients having different attitudes and responses to different aspects of their interactions with care providers and health services. To address this, satisfaction surveys have now moved away from using one or two questions to assess overall satisfaction, with more recently developed satisfaction surveys using multiple items to assess several different aspects of care.

As a consequence of the limitations of satisfaction surveys, many quality assessment tools now focus on assessing the occurrence of concrete and specific components of care during a specific timeframe.⁸ Questionnaires that take this approach are often referred to as patient experience surveys. In contrast to satisfaction surveys that assess patients' judgements on their interactions with their health care providers/health services, experience surveys aim to identify the events or processes that did or did not happen during the patient's care. It has been suggested that this approach is more able to identify intervention points for quality improvement services.⁹ However, to be useful as a method for improving care delivery, the events or processes assessed must be seen as important by consumers as well as health care providers and health services. To this end, development of these measures includes consultation with consumers and health care providers.

Tools assessing cancer patients' satisfaction with care or experiences of care are the focus of this review.

Patient Needs Assessments aim to identify areas where patients' believe additional care, support or resources are needed in order to achieve optimal wellbeing.^{4,10} There are a number of cancer specific needs assessments tools available with most measures assessing both the presence of an unmet need and the level of need (e.g. low, moderate or high). While most survey tools include items assessing aspects of care delivery, in general assessing care experiences is not the focus of these tools. Thus while they can provide information regarding the areas of support or care patients report a need in, they are not informative regarding the delivery of care received. Unmet needs surveys are not the focus of this review.

Quality of life is a multidimensional construct that can be assessed in terms of general quality of life or health related quality of life. Cancer specific measures of quality of life assess the impact of cancer on various domains including physical, psychological, social, vocational, and financial aspects of a person's life. Quality of life measures are widely used internationally, particularly in clinical trials, thus the potential to compare measures across different cancer populations is an advantage. Monitoring quality of life for cancer patients at the population level may provide valuable information about the burden of cancer and how this changes over time. However while they provide an indication of the impact of cancer on specific areas of a person's life, they are not informative regarding the individual's experience of care or where care could be improved. For example, two people may have identical pain scores, even though their experiences of care have differed substantially. Quality of life scales are not the focus of this review.

Critical points in the care experience

The Victorian Department of Health's management frameworks for cancer care have identified nine critical points in the cancer disease trajectory. These are:

1. At community level, recognition of potential cancer signs or symptoms or abnormal result from a screening test
2. Initial consultation with a GP
3. Referral to, and diagnosis by, appropriate clinical specialist
4. Determination of treatment program
5. Implementation of treatment
6. Follow up program
7. Recognition of disease recurrence and determination of treatment program
8. Implementation of treatment for recurrence
9. End of life care.

This review focuses on survey tools assessing care received at critical points 2 to 6 and refers to these critical points as care points along the care trajectory.

Victorian Environment

Victorian Patient Satisfaction Survey

The Victorian Patient Satisfaction Monitor (VPSM), a patient satisfaction and experience survey, has been used in Victoria since 2000.⁷ It samples patients who have been discharged from one of the 95 Victorian acute care public hospitals through hospital records. The recruitment procedure identifies categories of patients, for example 'acute', 'surgical' etc. but does not identify diagnosis. The purpose of the monitor is to provide hospitals with information that can be used to improve their services to patients, and to allow hospitals to compare their performance against similar hospitals.⁷ While we do not consider the VPSM in this review, it is important that any system to monitor the care experiences of cancer patients fit alongside the VPSM.

Studies undertaken by Integrated Cancer Services

Several Integrated Cancer Services have conducted their own investigations into the experiences of care among cancer patients in their catchment areas. A qualitative methodology is often used for this work including focus groups or open-ended interviews of patients and carers. These studies can provide the service with detailed information on the care issues patients consider important and can highlight aspects of care that are being done well or that could be improved. While useful for providing insight into the patient experience, qualitative studies are generally not the preferred method of studies that aim to monitor the prevalence of specific behaviours or outcomes. Quantitative studies are more suited to this as they can provide estimates of the percent of the target population reporting that specific events occurred during their care. In addition quantitative studies are more suited to determining the extent to which care has improved or deteriorated over time.

Several important findings can be extracted from the qualitative studies conducted by the ICS's to date. As these studies have involved people from rural areas of Victoria, their results highlight the areas of care that are important to this population. The findings from these studies highlight the importance of extended waiting times, lack of scheduling of appointments (especially for those who need to travel some distance to attend the clinic), perceived business of clinicians and the resulting perception that their consultations are time pressured and difficulty in obtaining information about different support services on patients experiences of care.¹¹ These reports offer another mechanism to review the items in the questionnaires discussed below to ensure that they cover most of the areas of care patients consider important.

Review aims and objectives

The overall aims of the literature review were to review measures assessing satisfaction with care or experiences of care specific to adult cancer patients in order to:

- inform development of a tool to quantitatively assess cancer patients' care experiences
- inform development of research method for the state-wide survey of cancer patients
- inform development of mechanisms/methods of feeding back results from survey to inform quality improvement in Victorian cancer services.

To this end the literature review focused on:

- Identifying current quantitative survey tools that assess cancer patients care experiences and determine: type of care assessed (e.g. inpatient or outpatient experiences), domains of care assessed, psychometric properties of tools and current use of tools
- Identify survey methodologies commonly used to assess patients' experience of care including: method of administering survey, characteristics of patients surveyed, timing of survey administration in terms of time since diagnosis or contact with health system, procedures for identifying sample
- Best practice options for communicating survey results to health services and health professionals to inform quality improvement.

REVIEW METHODOLOGY

Data sources: The literature review includes both published and grey literature.

Published literature search: The following databases were searched for relevant literature: MEDLINE, CINAHL, PsycLIT, PubMed. Only articles published in English were considered for this review. While searches focused on articles published since 2000, earlier articles were considered if they formed the basis of the development of survey tools reported in more recent publications.

A broad range of search terms and phrases were used to ensure a wide range of literature was initially identified. The search terms used to identify reports focusing on patient experiences/satisfaction were: Patient reported outcomes/patient experiences /patient satisfaction/unmet needs/care experiences/medical care quality assurance/health care/ hospital standards. These terms were crossed with terms relating to cancer, measurement and psychosocial including: Cancer/Oncology; Medical Oncology; Psychosocial; Measurement /survey/health care surveys; Adult.

Grey literature: Relevant grey literature was sourced from the website of key organisations that have conducted population-based surveys of cancer patients. Staff from these organisations were contacted when needed.

RESULTS

Survey tools to assess cancer patients' experiences of care or satisfaction with care

A number of survey tools developed since 2000 to assess the care experiences of people with cancer were identified (Table 1). The literature can be classified into two categories:

- Category 1) reports that discuss tools developed largely at academic institutions and seem to be used largely in research studies or have been recently developed for research;
- Category 2) reports that discuss tools used by a health related organisation (e.g. National Health Service in the UK) to monitor experiences of care at a population level with results from the survey feed back to service providers.

The importance of the PICKER Institute tools in this area was highlighted. Several Category 2 studies utilise PICKER instruments or organisations have worked with the PICKER Institute to develop their survey tool. The PICKER Institute approach to the assessment of patient experiences is discussed in the examination of Category 2 tools.

The surveys can also be categorised according to whether they assess care delivered at last care contact or care delivered across the care trajectory. While survey tools that focus on the last care contact generally assess the last inpatient experience, some also focus on the last outpatient experience.

Category 1: Tools reported in academic literature

Twenty-four papers published since 2000 were identified as reporting on 14 different cancer specific tools to assess patients' satisfaction with, or experiences of, care.^{9,10,12-25} In addition one scale that was not cancer specific is included in this review as it covered an area not covered in other scales but potentially important to experiences of care.²⁵

The 15 tools are listed in Table 1 along with the care point they assess and the cancer they target. Eight scales do not cover a specific care point, but rather cover either multiple points of care (e.g. from diagnosis to end of treatment) or an area of patient/health provider interaction that is applicable throughout the care trajectory (e.g. receipt of information).

Five of the 15 scales are specific to a particular cancer (Table 1), with three specific to breast cancer,^{9,12,13} one specific to prostate cancer²³ and one developed for lung cancer.²⁴ In general these scales cover multiple care points including diagnosis,

Table 1: Category 1 survey tools, tumour groups they target and type of survey.

Title of tool	Cancer group	Inpatient/ Outpatient/ Adjuvant therapy	Type of survey
Not tumour specific			
EORTC IN-PATSAT32 ¹⁴	All cancer patients	Inpatient	Satisfaction
EORTC OUTPATSAT-35 (separate versions for chemotherapy and radiotherapy) ¹⁵	All cancer patients	Outpatient	Satisfaction
EORTC QLQ-INFO25 ¹⁶	All cancer patients	No specific	Satisfaction
QUOTEchemo ¹⁷	All cancer patients	Adjuvant Therapy	Experience of care
Patient Satisfaction with Cancer treatment Education Questionnaire (PS-CaTE) (German) ¹⁸	All cancer patients	Not specific	Satisfaction
Satisfaction with Cancer Information Profile (SCIP) ¹⁹	All cancer patients	Not specific	Satisfaction
Cancer Therapy Satisfaction Questionnaire (CTSQ) ²⁰	All cancer patients	Adjuvant Therapy	Satisfaction
Princess Margaret Hospital Patient Satisfaction with Physician (PMH-MD) ²¹	All cancer patients	Outpatient	Satisfaction
Medical Care Questionnaire (MCQ) ²²	All cancer patients	Outpatient	Experience of care
Tumour group specific			
Prostate Care questionnaire for Patients (PCQ-P) ²³	Prostate cancer	Multiple care points	Experience of care
QUOTE-BC ¹³	Breast cancer	Multiple care points	Experience of care
Consumer Quality Index- Breast care (CQI-BC) ⁹	Breast cancer	Multiple care points	Experience of care
REPERES60 ¹²	Breast cancer	Multiple care points	Satisfaction
Indicators of patient centred care (IPCC) ²⁴	Lung cancer	Multiple care points	Experience of care
Not Cancer Specific			
Care Transition Measure (CTM) ²⁵	Not cancer specific	Transition from inpatient care	Satisfaction

treatment and co-ordination of care. Nine scales are suitable for all tumour types. Of these scales, one assessed inpatient care, three assessed outpatient care and two were phrased as assessing care related to adjuvant therapy rather than outpatient care per se. Three scales focused on provision of information and these scales assessed information at different points in the care trajectory most commonly diagnosis and treatment. No distinction is made between inpatient services and outpatient services.

As indicated one scale included is not specific to cancer. This scale assesses the transition from inpatient care.²⁵

Table 1 also indicates whether the tool assesses satisfaction with care or patient experiences. While most of the tumour specific tools assess patient experiences of care, most of the tools targeted at all cancer patients assess satisfaction with care.

Below a brief description of each of the tools, including their development is presented. Details for the survey tools, including number of items in the tool, area of care assessed and domains or subscales of the tool, are shown in Table 2. Table 3 summarises the psychometric properties of the scales. The psychometric properties of a scale provide information regarding whether the scale can adequately assess the areas of care it aims to assess. It provides an indicator of whether the scale will provide consistent results if administered to the same people at different times. Two key indicators are focused on here: internal reliability and test-retest reliability, Box 1 provides a brief definition on these measures.

Box 1: Definitions for internal reliability and test-retest reliability.

Measure	Interpretation	Test used
Internal reliability	Degree to items that are thought to measure the same general construct are related to one another. The goal in designing a reliable instrument is for scores on similar items to be related (internally consistent), but for each to contribute some unique information as well.	Usually measured by Cronbach's alpha with scores ranging between 0 and 1. While Cronbach alphas between 0.6 and 0.7 are acceptable, alpha values ≥ 0.7 are preferred as they indicate good reliability.
Test-retest reliability	Determines a survey's ability to produce the same score from the same person at two different points in time. Stability of scores is wanted when a construct is not expected to change over a certain time period. The test-retest reliability is usually the correlation between the two time point scores.	Scores higher than ≥ 0.70 considered to indicate good test-retest reliability

Table 2: Number of items, method of development, area of care and care domains assessed by each survey tool.

Title of tool	Number of items	Method of development	Area of medical care asked about	Domains/scales (numbers in each)
Not tumour specific				
EORTC IN-PATSAT32 ¹⁴	32	Based in part on existing patient satisfaction questionnaires, as well as interviews with oncology specialists about cancer patient.	Care and organisation of services	Doctors (11), nursing team (11), organisation of care and services (9), general satisfaction (1).
EORTC OUTPATSAT-35 ¹⁵	12	Based mainly on the EORTC INPATSAT32, with revision of some items to reflect outpatient settings.	Quality of care, treatment	Doctors, nurses and services, and care organisation.
EORTC QLQ-INFO25 ¹⁶	25	Based in part on existing patient satisfaction questionnaires, as well as interviews with oncology specialists about cancer patient	Treatment, level of information received, diagnosis	Information about the disease (4), medical tests (3), treatment (7), other services (4) and other single items (8).
QUOTEchemo ¹⁷	69	Literature review, focus group discussions and a categorisation procedure of 67 relevant topics into seven main themes, based on QUOTE ^{communication} .	Chemotherapy communication	Treatment related information (20), prognosis information (3), rehabilitation information (11), coping information (7), interpersonal communication (6), tailored communication (10) and affective communication (10)
PS-CaTE (German) ¹⁸	24	Translation from Canadian tool to a German tool, so included a lot of interpreter and translator work. 'Forward/backward' translation method was used.	Treatment	Satisfaction with information with cancer treatment (4); satisfaction with information regarding side effects (4); satisfaction with information regarding complementary therapies (3); satisfaction with information sources and the way information is provided (3); information sources utilised (2).
SCIP ¹⁹	23	Derived from a published measure known as the SIMS, with other items added from qualitative interviews with patients.	Treatment	Satisfaction with the amount and content of information received (14), satisfaction with the form and timing of information received (7), further information you wish you had of received (open ended 2).
CTSQ ²⁰	16	Review of responses from interviews with oncology patients, nurses and physicians.	Chemotherapy/ biological or targeted therapies	Expectations of cancer therapy (5), feelings about side effects (4), satisfaction with cancer therapy (7).
PMH-MD ²¹	29	Item generation, item reduction of repeat items, item testing and factor analysis and reliability and validity testing.	Outpatient doctor/patient interactions	Interpersonal skills, time spent with physician, information, physician relationship.
MCQ ²²	21	Literature review and consulting of expert panel.	Outpatient doctor/patient interaction	Communication (6), preferences for seeing the same doctor (4) and coordination (5).

Table 2 (cont.): Number of items, method of development, area of care and care domains assessed by each survey tool.

Title of tool	Number of items	Method of development	Area of medical care asked about	Domains/scales (numbers in each)
Tumour specific group				
PCQ-P ²³	112	Literature review of the experiences of patients with prostate cancer care, interviews with patients and service providers.	Care and treatment, current health	GP visits and referrals (17), hospital tests (19), diagnosis and treatment decisions (29), treatment and discharge (23), monitoring (13) and health and socio-demographic (6), other comments (5)
QUOTE-BC ¹³	23	Began with qualitative analysis, also used optimisation techniques based on results of a pilot study.	Quality of care, continuity of care, treatment	Patient education regarding postoperative treatment (5), services by the breast nurse (5), services by the surgeon (6), patient education regarding activities at home (3), Patient education regarding preoperative treatment related aspects (4) and 9 single items
CQI-BC ⁹	152 (includes 118 items assessing experience of care, the remaining 34 items are skip items, global ratings or opinions)	Focus group discussions with breast cancer patients, key stakeholder input.	Diagnosis, treatment,	Conduct of professionals during breast examination (7); Conduct of general practitioner (4); Conduct of nurses (5); conduct of surgeons (4); autonomy regarding treatment (4); autonomy regarding follow-up treatment (2); conduct of professionals during radiotherapy (5); information on radiotherapy (2); conduct of professionals during chemotherapy (4); information on chemotherapy (4); co-operation (5); accessibility of care (4), continuity psychosocial care (3); continuity physiotherapy (3), continuity rehabilitation (3).
REPERES60 ¹²	64	Literature review and focus groups involving breast cancer patients.	Access to doctors, competence of doctors, information provision, experiences of care	Access to primary care (7); access to secondary care (3); competence and communication skills of primary care doctors (4); competence and communication skills from specialists (6); choice among different doctors (4); human qualities shown by doctors (4); global satisfaction (4); cover for medical expenses (5); listening abilities and information from doctors (7); organisation and follow-up of medical care (5); psychosocial support (5); material environment (4)
IPCC ²⁴	26	Combination of recommendations from guidelines and literature review and consultation with patients.	Diagnosis, treatment, experiences of care	Access (2), follow-up (3), communication and respect (1), patient and family involvement (6), information (3), coordination of specialists (3), coordination of oncology nurses (3), physical support (1), emotional support (4).
Not cancer specific				
CTM ²⁵	15	Began with focus groups involving older patients and their caregivers who had recently experiences post-hospital transitions, followed by item construction, evaluation and revision.	Transitions from hospital to home/outpatient care	Information transfer, patient and caregiver preparation, support for self management, empowerment to assert preferences.

Table 3: Selected psychometric properties of Category 1 survey tools.

Title of tool	Internal consistency Cronbach alpha scores	Test-retest reliability	Reading age	Feasibility	Mode of administration
Not tumour specific					
EORTC IN-PATSAT ³² ¹⁴	0.80 to 0.97 (except for the hospital access scale = 0.67).	A consecutive sample of 100 patients completed survey again after 2 weeks	Adult	Short survey, not sure if it is specific enough to cancer.	Paper and pencil
EORTC OUTPATSAT-35 ¹⁵	Ranged from 0.70-0.97 for all scales except environment.	NA	Adult	Quick and efficient survey tool.	Paper and pencil
EORTC QLQ-INFO25 ¹⁶	0.70 and above was found for all scales.	Small sample completed the survey 1 month after treatment and again 7 days later, excellent results.	Adult	Quick and efficient survey tool.	Paper and pencil
QUOTEchemo ¹⁷	Ranged from 0.72 to 0.92 on both subscales.	NA	Adult	Medium length, all Likert scales.	Paper and pencil
PS-CaTE (German) ¹⁸	Mostly above 0.80.	NA	Adult	Short and easy to complete	Paper and pencil
SCIP ¹⁹	Both subscales demonstrated that scales tap complimentary facets.	NA	Adult	Short measure, only looking at satisfaction with information	Paper and pencil
CTSQ ²⁰	>0.75 for three retained scales	A sub-sample of 88 participants completed follow up questionnaires 1 week after baseline. Test-retest reliability acceptable.	Adult	Short measure, only looking at cancer therapies, no surgery.	Paper and pencil
PMH-MD ²¹	Ranged from 0.60 to 0.96.	NA	Adult	Respondent burden is minimal.	Paper and pencil
MCQ ²²	Ranged from 0.69 to 0.84 across scales.	NA	Adult	Short and efficient	Paper and pencil
Tumour group specific					
PCQ-P ²³	Ranged from 0.63 to 0.80.	296 patients were posted the PCQ-P questionnaire again three weeks later.	Adult	Single sections can be used independently, short version also available.	Paper and pencil
QUOTE-BC ¹³	Found to be satisfactory	NA	Adult	Short, all Likert scales.	Paper and pencil

Table 3 (cont.): Selected psychometric properties of Category 1 survey tools.

Title of tool	Internal consistency Cronbach alpha scores	Test-retest reliability	Reading age	Feasibility	Mode of administration
CQI-BC ⁹	Ranged from 0.68 to 0.93.	NA	Adult	NA	Paper and pencil
REPERES-60 ¹²	For 11 scales >0.82; for global satisfaction 0.74	172 participants completed the same survey twice within 1 to 2 weeks apart. Test-retest was conducted a year after completion of initial treatment. Reproducibility was good.	Adult	Short and efficient	Paper and pencil
IPCC ²⁴	Seven out of eight domains > 0.65.	NA	Adult	Short and efficient, only specific to non-small cell lung cancer patients	Paper and pencil
Not cancer specific					
CTM ²⁶	Overall scale 0.93.	NA	Adult	Short and efficient, telephone method may be time consuming	Telephone interviewing

Survey tools: not tumour specific

EORTC: IN-PATSAT32/QLQ-SAT32/OUTPATSAT-35

The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group developed these survey tools. This organisation is responsible for the development of several well-used Quality of Life survey tools that are commonly used in clinical trials. The IN-PATSAT32,¹⁴ QLQ-SAT32¹⁵ and OUTPATSAT-35²⁷ are the same or similar survey tools. The IN-PATSAT32 is the more recent name for the QLQ-SAT32 and this is a more recent version of the Comprehensive Assessment of Satisfaction with Care survey.²⁸ The OUTPATSAT-35 is a modified version of the IN-PATSAT32, with questions phrased to assess outpatient care.

The EORTC-IN-PATSAT32 is a 32-item survey assessing perceptions of quality of care delivered by hospital doctors and nurses, along with assessments of quality of services and organisation of the hospital and one overall quality rating. Items for the scale were derived from other satisfaction questionnaires and interviews with patients and oncologists. Four scales are produced for the nurse and doctor items focusing on technical skills, interpersonal skills, information provision and availability (see Table 2). Psychometric properties of the scale and subscales (Table 3) are very good to excellent.

The scale assesses patient perceptions of care delivered during their most recent in-patient hospital stay. By assessing the ward the patient was admitted to and the reason for hospital admission, the tool can provide feedback on the quality of care patients received from doctors and nurses in specific areas of a hospital. However while the tools were developed for cancer patients, none of its items make specific reference to cancer or to specific treatments that may be received as part of cancer care.

The scale is reported in several papers describing its psychometric properties and the appropriateness of the scale for use in different countries.^{29,30,31}

The EORTC OUTPATSAT-35 is a modified version of the IN-PATSAT32. The OUTPATSAT-35 includes most of the items from the IN-PATSAT32 with instructions modified to reflect outpatient rather than inpatient care. The questionnaire takes two forms: one for chemotherapy and the other for radiotherapy. The questions in the two versions are the same, with the instructions differing to reflect the care episode assessed. The only English language paper reporting on the OUTPATSAT-35 reports on the psychometric properties of a Spanish version of the questionnaire used with ambulatory radiotherapy patients.²⁷ Psychometric properties of the scale for the Spanish sample are shown in Table 3 with internal reliabilities ranging from good to excellent.

EORTC QLQ-INFO25

This survey tool has also been developed by the EORTC Quality of Life Group. The scale was specifically designed for cancer patients and aims to assess level of information received during different points of care and satisfaction with information received.¹⁶ Development of the tool involved a review of the literature to identify issues identified regarding information delivery to cancer patients, patient and health professional review of the list of issues to determine appropriateness and comprehensiveness, development of items from the reviewed list, further review of items by patients and health professionals. This work produced a 26 item scale that was further tested with patient to ensure items were worded appropriately and that the tool covered all appropriate areas. A larger quantitative study was then conducted to examine the psychometric properties of the 26 item scale.¹⁶ This study tested the items with 509 patients. One item was removed from the scale with the remaining items forming the EORTC INFO25 scale. The scale has 4 multi-item subscales and 8 single items (see Table 2).

QUOTEchemo

The QUOTE^{chemo} tool is part of the QUOTE (QUality Of care Through the patient's Eye) family of standardised and validated survey tools developed to assess quality of care.¹⁷ The QUOTE survey tools conceptualise patient's experiences of care along two dimensions: i) how important or significant a specific health care event or aspect is to the patient and ii) patients' experiences with regards to that event or aspect of care. According to the QUOTE authors combining these two dimensions reveal the "qualities in health care that people desire". QUOTE^{chemo} is a patient centred instrument to assess needs and actual experiences with communication preceding chemotherapy treatment. Items for the survey instrument were derived from three different sources: i) the QUOTE^{communication} questionnaire, ii) a literature review and iii) interviews and focus groups with patients. The initial 69 items were classified into 7 dimensions by researchers. Factor analyses confirmed the seven dimensions but suggested the removal of two items that did not load significantly onto any dimension (see Table 2 for dimensions). The final survey consisted of 67 items. The psychometric properties of the scale were good to very good with internal consistency of the subscales ranging from 0.72 and 0.92.

The QUOTE^{chemo} assesses both the aspects of information patients consider important to receive before starting chemotherapy and whether they received this information. The tool can provide an indication of gaps in information provision in this care point. The tool provides a good measure of information experiences for patients undergoing chemotherapy. However the survey's focus on only one area of care means it cannot be used to assess overall care experiences of people with cancer.

Patient Satisfaction with Cancer Treatment Education Questionnaire (PS-CaTE) (German Translation))

The paper included in this review reports on the German translation of the Canadian developed above named questionnaire.¹⁸ We were unable to find a published report on the original development work for this questionnaire. The German study was conducted to examine the psychometric properties of a German version of the PS-CaTE. The PS-CaTE was designed to measure patients' satisfaction with the information they received within the framework of a cancer treatment education programme. The PS-CaTE two sections containing: i) perceptions of the information given during cancer treatment and ii) information sources utilised by patients. The 14 items evaluating perceptions of cancer information were found to form 4 multi-item subscales (see Table 2). Psychometric properties for the first three subscales were excellent, with the psychometric properties of the fourth subscale adequate (Table 3).

The scale is a satisfaction survey. Its focus on information provision, limits its use as a means to monitor patients' experiences of medical care.

Cancer Therapy Satisfaction Questionnaire (CTSQ)

This questionnaire was originally designed to assess satisfaction with chemotherapy treatment¹⁹ and has since been extended to assess satisfaction with hormonal and targeted therapies as well.³² The original scale¹⁹ was developed from findings of qualitative interviews with cancer patients in the USA, UK and France, along with the findings from focus groups and interviews with oncology nurses and doctors from these countries. In contrast to other questionnaires discussed here, this questionnaire assesses expectations of treatment as well as aspects of having treatment (e.g., side effects, convenience of therapy). The underlying premise of the questionnaire is that satisfaction judgements are influenced by both expectations of the efficacy of the treatment and likelihood of side effects. The CTSQ is the only questionnaire reviewed here to specifically assesses patients' expectations of the treatment in terms of disease remission or elimination of the disease. The original version of the scale had 21 items forming 5 multi-item domains.

A validation study examined the psychometric properties of the 19-item questionnaire (questions assessing not taking medication were removed).³² This study also extended the scale to hormone and targeted therapy by replacing the term chemotherapy with the more generic cancer therapy (IV/pills). Factor analyses reduced the items in the scale from 19 to 16 with the removal of one item and a two-item subscale (convenience of therapy). Domains for the final 16 items version of the scale are shown in Table 2. Psychometric properties of the three subscales are good to very good (Table 3).

The questionnaire assesses overall satisfaction with having chemotherapy or biological/targeted therapy. While items in the questionnaire address management of side effects and whether they considered stopping treatment, the questionnaire does not assess actual delivery of the therapy and patient/medical staff interactions before during or after treatment (either individual sessions or period of therapy). This tool cannot determine quality of care at key points in the interaction between patients and the medical team in the delivery of chemotherapy or biological therapies.

Satisfaction with Cancer Information Profile (SCIP)

This survey tool assesses cancer patients' (primarily head and neck cancer) satisfaction with the information received about treatment (Llewellyn et al 2006).²⁰ The development of the Satisfaction with Cancer Information Profile (SCIP) drew on an existing tool - the Satisfaction with Information about Medicines Scale (SIMS)³³ - and findings from qualitative interviews with patients. The scale contains 23 items and consists of two subscales (Table 2). The original article examining the scale's psychometric properties found it to have good internal reliability (Table 3), good concurrent, predictive and discriminant validity. However, a later study used factor analysis to determine whether the items in each subscale formed one scale or several different scales. Results suggested that items in subscale 1 formed three different subscales named: information on unwanted side effects; information on long term effects and information on social and financial support.

The scale provides good information regarding patients' satisfaction with the level of information they have received. However as it focuses on only one aspect of care – delivery of information- it cannot be used alone to assess patient experiences of care.

Princess Margaret Hospital Satisfaction with Doctor (PMH-MD)

The aim of this tool is to assess patient satisfaction with the relationship they had with their doctor at their last visit to an outpatient clinic.²¹ The tool was designed to assess satisfaction of outpatients with cancer. The items for the tool were derived from a mix of sources, including the researchers, existing measures and interviews with outpatients attending clinics. Patients reviewed similarly worded items and the item most clearly worded was retained. Patients were also asked to rate the items in terms of importance for influencing satisfaction with their visit with the doctor and how strongly they agreed or disagreed with the items. Items that were deemed not important or did not show variance in agreement levels were removed from the scale. Quantitative testing of the 41-item preliminary scale reduced the number of items to 29. Factor analyses suggested the 29 items formed 4 subscales (i) information exchange (10 items); ii) interpersonal skills (8 items), iii) empathy (6 items) and iv) quality of time (5 items)). The internal reliabilities of the subscale and the scale overall were high (see Table 3).

A subsequent quantitative study was conducted to confirm the factor structure of the 29-item PMH-MD scale.³⁴ This study involved a smaller sample than the original study and produced a different factor structure for the scale. This study found that 24 of the original 29 items loaded onto 2 factors that were called i) doctor disengagement (13 items) and ii) perceived support (11 items). All items from the original information exchange subscale loaded onto the new perceived support scale along with one of the empathy items. The new doctor disengagement subscale was formed from four of the five quality of time items, seven of the eight interpersonal skills items and two of the six empathy items. Test-retest reliability of the new scale and its two subscales were acceptable with reliability being higher for the two subscales ($r > 0.75$) than the overall scale ($r = 0.60$). Internal reliability was also higher for the two subscales than the overall 24-item scale (see Table 3).

The scale's focus on interactions with their outpatient doctors interactions, limits the utility of this instrument in assessing cancer patients' experiences of care. In addition while the scale was intended as a cancer specific measure, the authors have noted

that none of its items are specific to cancer treatment. This may be a limitation of the survey as it suggests it is a generic measure of patient satisfaction with their interaction with doctors rather than looking at specific cancer related interactions. As an increasing number of cancer patients are receiving treatments like chemotherapy as outpatients, a tool that does not assess care in the different outpatient settings may not be appropriate for assessing quality of cancer care.

Medical Care Questionnaire (MCQ) for Oncology Outpatients.

The focus of this 15-item scale is patients' perceptions of the continuity of care among oncology outpatients.²² The scale was developed in the UK from an existing questionnaire assessing continuity of care in primary care setting. The development of the questionnaire involved: 1) a review of the literature to identify continuity of care issues for oncology patients and to identify existing scales; 2) review of existing scale by medical oncologists to remove or modify items to ensure their applicability in the oncology outpatient setting; 3) quantitative test of modified scale with sample of patients and assess properties of scale; 4) quantitative test of modified scale with new group of patients to determine psychometric properties of revised scale. From the original 19-item questionnaire, three items were removed and 5 added after review by medical oncologists. Six items were removed after a review by patients, leaving 15 items. The 15-item scale was subjected to factor analyses using data from two patient studies. Factor analyses showed that the items formed three subscales assessing communication, preferences for seeing the same doctor, and co-ordination (see Table 2). Psychometric properties of the subscales are good (see Table 3).

The MCQ assesses experiences of care with items focusing on care received from different doctors within a specific clinic. The scale does not address patients' experiences of continuity of care from doctors from different departments or clinics (e.g. radiotherapy or chemotherapy). This is a limitation of the scale.

Survey tools: tumour specific

Prostate Care Questionnaire for Patients (PCQ-P)

The Prostate Cancer Questionnaire-Patients (PCQ-P) was developed in the UK to assess the experience of care of men with prostate cancer.²³ The work has also developed a carers' version of the questionnaire although this is not discussed here. The PCQ-P assesses care experiences from diagnosis to follow-up. Items for the questionnaire were derived from interviews with patients and health professionals and reviews of the literature to identify important domains of care for men with prostate cancer. A long and short form of the survey exists with the long version containing 107 items plus 5 items allowing comments on different aspects of care, while the short version contained 31 items including demographic questions and one item asking for other comments.

The long version of the survey contains six sections covering: A) doctor experience when first seen for possible prostate problems; B) having tests for possible prostate cancer; C) diagnosis and treatment decisions, D) receiving treatments, E) being monitored and F) demographic and general health. The number of items in each section differs. The number of questions in each of the sections differs. While in

general questions in the different sections differ to reflect aspects of care important at that treatment stage, items assessing waiting times, interactions with nurses and doctors (e.g. receipt of information, treated considerately) and hospital/treatment centre environment are included in several sections.

A quantitative study involving 865 men was conducted to determine the psychometric properties of the instrument as well as its acceptability among patients. Interviews with patients suggested the questionnaire was acceptable with questions reported as easy to understand and complete. Only 2 of 20 patients thought the questionnaire was too long. Cronbach's alphas for the five sections ranged from 0.63 to 0.80. However given the diversity of items in the sections (e.g. in section C, items ranged from waiting times information provision, to staff working well together) lower Cronbach alpha scores may not be surprising. However Cronbach alpha scores greater than 0.60 are still considered adequate.

As indicated the questionnaire assesses experiences of care. As the questionnaire covers care from initial interaction with general practitioner/doctor regarding possible prostate problems to treatment of prostate cancer and monitoring/follow-up, the survey provides an avenue to assess care throughout the care trajectory. However, as the questions in the survey are specific to the care of men with prostate cancer, it cannot be used as a general tool to assess all cancer patients' experience of care.

QUOTE-BC

A recent addition to the QUOTE family of surveys is the QUOTE-BC This survey instrument has been reported in a recent paper¹³ and was designed to measure the quality of breast cancer care as reported by patients. Items were derived from focus group discussions with women with breast cancer, with 72 health care items initially developed. A quantitative study explored the psychometric properties of the 72-item survey. After factor analyses, analyses of missing data and identification of items patients found ambiguous, the survey was reduced to 33-items. The revised survey contained 5 multi-item subscales and 9 single separate items (see Table 2). The psychometric properties of the subscales as indicated by Cronbach alphas were good (see Table 3).

The items in the scale cover many aspects of care that are not included in other scales. For instance, this scale includes items assessing whether the woman received about a possible drain or prosthesis, whether test results were available at appointments and waiting time for surgery.

The QUOTE-BC has several strengths. It assesses patient experiences of care rather than satisfaction; it assesses whether patients were treated with respect and whether information was provided pre- and post-treatment. However there are also limitations to the content of the questionnaire. Few items assess the provision of chemotherapy and/or biological/targeted therapies. Additionally few items address delivery of care at different stages in the treatment trajectory. This later limitation reduces the utility of the questionnaire as a tool that can assess the quality of care throughout all stages of cancer care for the purpose of providing feedback.

Consumer Quality Index-Breast Care (CQI-BC)

The Consumer Quality Index-Breast Care (CQI-BC)⁹ is part of standardised assessment of patients' experiences conducted in the Netherlands using the Consumer Quality Index (CQ-Index) surveys. These surveys are based on two families of surveys: i) the American Consumer Assessment of Healthcare Providers (CHAPS see below) and ii) the Dutch QUOTE (Quality of Care through the patients' eye) instruments. The CQ-Index family of surveys assess patients' experiences of care rather than satisfaction with care received. While several disease specific CQ-index instruments have been developed, the only cancer specific instrument in the published literature is for breast care: the CQI-BC. The scale is aimed at both benign and malignant breast disease.

Items for the CQI-BC were derived primarily from focus group discussions with women with breast cancer and existing questionnaires on breast care experiences. Psychometric analyses were undertaken on a 234-item pilot version of the questionnaire. This was reduced to a scale consisting of 118 experience items of which 88 were also rated on an importance scale. The scale consisted of 15 multi-item experience subscales with good to very good internal reliability (see Table 2 for list of subscales and Table 3 for psychometrics). Items in the questionnaire cover care from diagnosis to after treatment (e.g., information on rehabilitation, information on return to daily activities), as well as assessing accessibility (including waiting times and hospital contact by phone/email), and co-operation and continuity of care between different caregivers (including receiving contradictory information).

The specificity of this questionnaire for breast care limits its use for a survey of all cancer patients.

REPERES-60

The REPERES-60¹² is a 60-item questionnaire developed to assess satisfaction with care among women diagnosed with early breast cancer in France. Items in the tool were derived from an existing satisfaction with care tool (the Consumer Satisfaction Survey (CSS) as well as from findings from focus groups with women with breast cancer and discussions with breast care experts. This work developed a 121-item questionnaire (45 new items and 76 items from the CSS) that was tested in a quantitative study involving 850 respondents. Analyses of this data indicated that 57 items could be removed due to them either having a high non-response rate or having high correlations with other items. The remaining 64 items were subjected to factor analysis which indicated that a further four items could be removed. The resulting 60-item tool (39 items from the CSS and 21 newly developed items) comprised 12 subscales listed in Table 2. The scale covers the care trajectory, and includes issues of communication and competence of primary care doctors, psychosocial support, treatment environment, insurance coverage and listening abilities and information provided by doctors. The psychometric properties of the scale and subscales are good to high, and test retest reliability is good (Table 3).

A limitation of the tool is its failure to clearly assess care at different points in the care trajectory. The survey addresses issues of relevance to patient care (e.g. information provision, psychosocial support etc.) however it asks about these issues generally rather than at specific care points (e.g. at surgery, radiotherapy etc.). A further

limitation of the survey tool is its failure to differentiate specialist care from surgeons, radiation oncologists or medical oncologists. Instead questions group all specialists together. In addition, the survey largely ignores care delivered by nursing or other allied health professionals. However the inclusion of items assessing satisfaction with GP care, organisation of care (items assessing time taken to received treatments and communication between doctors) and the physical environment in which care is delivered is a strength of the survey tool.

The tool's focus on breast cancer care limits its usefulness for a study of the care experiences of all cancer patients.

Indicators of Patient Centred Care (IPCC)

The Indicators of Patient Centred Care²⁴ was developed as a tool to assess the patient centredness of cancer care. The survey tool was developed in several stages. The stages included: reviewing evidence based guidelines for the physical, emotional and social care of patients to extract key indicators of care; obtaining ratings of the importance of each indicator from patients with head and neck cancer and lung cancer on a 9-point scale, removing items with mean rating score below 8. This process resulted in a set of 56 indicators of patient centred care. Table 2 shows that these 56 indicators formed 8 domains (e.g. access to care, follow-up, communication and respect etc. Psychometric properties of the 56 indicators were examined in a sample of 100 non-small cell lung cancer patients and reduced the set of indicators to 26 items spread across the 8 original domains. Internal reliabilities for 5 of the 6 multi-item domains were acceptable (Table 3). One subscale has a Cronbach's alpha score of 0.22, indicating that the two items in this subscale did not assess one underlying dimension. Despite their low internal reliability these items were retained.

Despite the set of indicators being tested and developed with lung cancer patients in mind, no items in the set are specific to lung cancer care. Thus it may be possible to use the set of indicators (with minimal changes in wording of some items) with a broader range of patients. However testing of the items to determine their suitability with other tumour groups would be needed.

Non-cancer specific tool

Care Transitions Measure (CTM)

The CTM²⁵ focuses on the experiences of patients when transitioning from hospital care to the next care phase. The scale was not developed for cancer patients specifically but rather was tested on patients with heart disease, stroke and hip fracture. The scale consists of 15 items developed from focus group discussions with patients and their caregivers/support persons. From this work, items in the Care Transitions Measure assessed four domains of care: information transfer, patient and caregiver preparation, support for self-management and empowerment to assert preferences. A subsequent psychometric study confirmed that the scale had 4 multi-item subscales that reflected the domains of care identified in the focus groups (see Table 2 for subscales). Further factor analyses also suggested that the subscales loaded onto one uni-dimensional scale. The internal reliability of the 15-item measure was excellent (Cronbach alpha=0.93). A three-item version of the scale has recently

been developed³⁵ that explained 88% of the variance in the 15-item scale. This suggests that the 3-item CTM is a good alternative to using the longer survey.

The scale focused on experience of being discharged from an inpatient stay within a hospital. As the scale asks patients to indicate whether specific events happened, it can be considered an experience of care tool rather than a satisfaction measure.

While several of the other scales discussed above contain a section assessing follow-up care or continuity of care, few explicitly examine how well prepared patients felt when discharge from hospital. While the usefulness of this scale may be limited for many cancer patients who receive chemotherapy and/or radiotherapy as outpatients, assessing patients' experiences of transitioning from this treatment to their next or to no treatment may be an important aspect of care to consider.

Type of questionnaire and response scale.

As indicated in Table 1, most scales discussed in this section assess satisfaction with medical care, with only 5 questionnaires assessing patient experiences of care (QUOTE^{chemo}, PCQ-P, QUOTE^{-BC}, CQI-BC; IPCC). Of these, four questionnaires are tumour specific tools (PCQ-P, QUOTE^{-BC}, CQI-BC; IPCC).

Satisfaction questionnaires: A variety of response scales were used across these questionnaires (Table 4). Generally responses are made on a likert type scale with responses reflecting judgements on services received (e.g. "excellent" to "very bad"; "too much" to "too little", "very satisfied" to "very dissatisfied").

Experience of care survey: A characteristic of these surveys is that they ask patients to report whether events happened during their care interactions. In general response scales used are frequency type scales (e.g., "never" to "always") or scales indicating whether an event happened or not (e.g., "yes"/"no").

In addition to the frequency response, surveys based on the QUOTE family of tools (QUOTE^{chemo}, QUOTE^{-BC}, QCI-BC) also respond to items on an importance scale. As shown in Table 4, the three studies use a 4-point likert-type scale to assess importance of item that ranges from 1) not important to 4) very important. Items are then rated on a frequency scale (either a binary (yes/no) scale or the 4-point scale of "never", "sometimes", "usually", "always").

Items in the IPCC tool were phrased in the form of a question regarding whether something happened (e.g. Nurses involved family and friends during care and follow-up). Items were responded to on a 4-point likert-type scale ranging from "not done" to "done excellently".

As current practice for assessing quality of care suggests that survey instruments should focus on assessing experiences of care rather than satisfaction, a survey tool for use in the state-wide survey should assess whether an aspect of care happened or not.

Table 4: Type of survey and response scales used for questions.

Title of tool	Scale Type	Response options
Satisfaction tools		
EORTC-INPATSAT 32 ¹⁴	5-point Likert scale	Poor, Fair, Good, Very Good, Excellent
EORTC-OUTPATSAT-35 ¹⁵	5-point Likert scale	Poor, Fair, Good, Very Good, Excellent
EORTC-QLQ-INFO-25 ¹⁶	4-point Likert scale	Not at all, a little, quite a bit, very much
PS-CaTE ¹⁸	5-point Likert scale	Strongly disagree, disagree, Uncertain, Agree, Strongly agree
SCIP ¹⁹	Subscale 1: 4-point scale Subscale 2: 5-point scale	Too much, about right, too little, none wanted. Very satisfied, satisfied, neither, dissatisfied, very dissatisfied.
CTSQ ²⁰	11 items 5-point scale 8 items 5-point likert scale: different anchoring for each item	Always, Most of the time, sometimes Rarely Never i) Very convenient to very inconvenient ii) Very bothered to not bothered at all iii) Very worthwhile to not worthwhile at all iv) Much more difficult than I thought to much easier than I thought v) Much better than expected to much worse than expected (2 items) vi) Very satisfied to very dissatisfied (2 items) vii) Yes definitely to definitely not
PMH-MD ²¹	4-point likert type scale	Strongly agree to strongly disagree with a not applicable response option.
REPERES-60 ¹²	5-point likert scales	56 items: Bad, fair Good, very good excellent 4 items: Completely agree; agree generally, no marked opinion, do not really agree; do not agree at all.
MCQ ²²	Not reported	Not reported
CTM ²⁵	4-point likert type scale	Strongly agree, agree, disagree, strongly disagree

Table 4 (cont): Type of survey and response scales used for questions.

Title of tool	Scale Type	Response options
Experience of care tools		
QUOTE-BC ¹³	Two response scales 4-point likert type scale assessing importance Mix of 4-point likert scales and yes/no scales assessing Experience response option	Not important, fairly important, important, very important. Never, sometimes, usually, always Plus for some "not applicable/I don't know" Yes/No
CQI-BC ⁹	Two response scales: 4-point likert type scale assessing importance Mix of 4-point likert scales and yes/no scales assessing Experience. Three point scale assessing how much of a problem something is	Not important, fairly important, important, very important. Never, sometimes, usually, always Plus for some "not applicable/I don't know" Big problem, small problem or no problem
PCQ-P ²³	Various	Scales vary for different items
IPCC ²⁴	4-point likert scale	Not done, done but inadequately, done adequately, done excellently.

Comparison of Scales

All survey tools discussed above follow similar developmental processes of deriving items from existing tools or literature reviews and by consulting with relevant patient groups and health professionals to identify other items and confirm appropriateness and importance of items. This development process follows that recommended by the PICKER Institute (see below) and other peak bodies for survey development. As both patients and health professionals were involved in the identification of items for the different survey tools, all tools should address issues of importance for quality patient care. As might be expected from a review of scales reported in published papers, the psychometric properties of all scales were, in the main, good to excellent.

The areas of care that at least some items in the different survey address are shown in Table 5. As only five of the survey tools cover multiple care points, it is important to note that the areas of care shown in the table may only be assessed at one specific care point. For example the areas of care covered by the QUOTE^{chemo} only relate to chemotherapy and not all critical care points. The tools that cover the greatest number of areas are the cancer specific surveys: PCP-P for prostate cancer and CQI-BC for breast cancer. In addition in the main these survey tools cover critical care points 2-6 in the Patient Management Frameworks. The survey tools that addressed the least number of care areas were the CTM, PMHSD and the CTS). The lower number of care areas addressed by these tools most likely reflects that they address a specific area of care, (eg the transition from hospital care for the CTM and chemotherapy and biological therapy satisfaction for the CTS).

All Category 1 survey tools have some limitations that reduce their appropriateness for use in a state-wide survey of all cancer patients. The main limitations are that they focus on a specific tumour group or assess only a very limited number of care points or they focus on one aspect of care (e.g. communication). For example the QUOTE^{chemo} survey tool is only appropriate for patients having chemotherapy and only assesses one aspect of care during this treatment, while the SCIPs tool only assesses satisfaction with receipt of information. Only the cancer specific survey tools assess care experiences over a range of care points. However as many of the items in these tools are specific to the cancer they study, development work would be needed to transform these scales into questionnaires that could be utilised with any and all cancer patients.

Table 5: Comparison of areas of care items address in different Category 1 survey tools.

	EORTC IN-PATSAT	EORTC INFO25	EORTC OUTPAT-SAT	QUOTE chemo	QUOTE breast	PCQ-P	PS-CaTE (German)	SCIP	CTSQ	CQI-BC	PMH-MD	REPERES 60	MCQ	IPCC	CTM
Access to care	Y				Y	Y				Y		Y	Y	Y	
GP	Y					Y				Y				Y	
Doctors	Y	Y	Y		Y	Y				Y	Y	Y	Y	Y	
Nurses	Y	Y	Y		Y	Y				Y				Y	
Information provided	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	
Choice among doctors				Y		Y						Y	Y		Y
Empathy and support from doctors/nurses	Y		Y	Y	Y	Y				Y	Y	Y	Y	Y	
Overall satisfaction	Y	Y				Y	Y			Y		Y			
Financial support						Y		Y				Y			
Follow up care						Y		Y		Y		Y		Y	
Psychological support				Y	Y	Y		Y		Y		Y		Y	
Support for self-care		Y		Y	Y	Y				Y	Y			Y	Y
Understanding medication				Y		Y			Y					Y	Y
Management of pain	Y				Y	Y		Y	Y					Y	
Side effects of treatments	Y			Y	Y	Y	Y	Y	Y					Y	
Shared decisions				Y	Y	Y	Y			Y	Y			Y	Y
Future care plan		Y		Y	Y	Y	Y	Y		Y			Y	Y	Y
Transition/coordination of care	Y				Y	Y				Y			Y	Y	Y
Involvement of carer/family				Y	Y	Y		Y						Y	
Waiting times	Y		Y		Y	Y				Y	Y			Y	
Examinations/diagnostic tests		Y	Y	Y	Y	Y				Y					
Radiotherapy		Y				Y				Y					
Chemotherapy		Y	Y	Y		Y			Y	Y					
Other services i.e. Physiotherapy		Y	Y			Y				Y					

Conclusions and Recommendations

The survey tool for the state-wide survey should assess experiences of care rather than focus only on assessing satisfaction with care.

Most Category 1 survey tools assess satisfaction with care rather than patient experiences of care

There is a need to determine the critical care points that the state-wide survey aims to address. This will assist in identifying an appropriate survey tool.

No Category 1 survey tool covers all critical care points.

As the Category 1 survey tools that assess patients' experiences of care are tumour specific or assess only one area of care, no existing Category 1 survey tool can be recommended for use in a state-wide survey of all cancer patients.

Methodology employed to develop Category 1 scales

The section below focuses on the method used to quantitatively test the scales shown in Table 1. As the aim of these studies is generally to recruit sufficient patients in their target group to conduct a quantitative study of their survey, the methodologies used for these studies may not be appropriate for a population-based study. In this section we focus on describing how these studies identified patients, how eligible participants were approached, survey delivery methodology and response rates. This will provide further information on the survey tool's target group, and will highlight methodological issues that may need to be considered when recruiting patients for a state-wide survey.

Recruitment and response rates

As can be seen from Table 6, 13 of the 15 studies identified participants through hospital/health clinic records. The studies that did not use this method utilised health insurance claims to identify participants (QUOTE^{BC}) or distributed questionnaires using a mix of methods but mainly through self-aid groups (peer support groups) (PS-CaTE). The studies with the highest response rates used a recruiter located at the hospital/clinic to approach eligible participants about the study. The lowest response rate was achieved for the QUOTE^{BC} with only 49% of questionnaires returned. This low response rate may be due in part to this study not including any reminder approaches. All other studies that approached participants included one or two reminder approaches.

If a mail-out approach to participants is adopted, two reminder letters should be incorporated into recruitment procedures.

Table 6: Method of recruitment, response rates and age of samples used for quantitative studies testing the Category 1 survey tools.

Title of tool	Tumour group	Age of sample	Method of recruitment	Care point for recruitment eligibility	Number of surveys sent/returned	Response Rate
Not tumour specific						
EORTC IN-PATSAT ¹⁴	All tumour groups,	18+	Hospital records: approached in person before discharge	Hospitalised in surgery or medical oncology ward for at least 3 days	762 sent, 647 returned	85%
EORTC OUTPATSAT-35 RT ¹⁵	All tumour groups	18+,	Hospital records: approached in person at clinic	Need to have received at least 3 weeks of radiotherapy.	106 approached, 100 participated	94%
EORTC QLQ-INFO25 ¹⁶	All tumour groups	18+,	Hospital records: approached in person at clinic	(I) newly diagnoses received first treatment line of radio/chemo therapy; (ii) recurrent disease starting second (or other) line radio/chemo therapy	509 participated in first survey, 432 completed second survey also	85%
QUOTEchemo ¹⁷	All tumour groups	18+	Hospital records: mail	New to chemotherapy but doesn't need to be first session (patients on average 7 months after start of CT).	582 sent, 345 included in analysis	59%
PS-CaTE (German) ¹⁸	All tumour groups	18+	Distributed to patients at hospitals, oncology practices, hospital pharmacies and self-aid groups across Germany.	Not reported	Numbers sent out not specified. 232 responses received for main survey:	response for self-aid approach 65%
SCIP ¹⁹	All tumour groups	23-89 years	Hospital records: mail	From sample recruited for previous study - 82 newly diagnosed patients with head and neck cancer. Survey completed after diagnosis but before treatment	82 participated in first survey, 68 completed second survey also	76%
CTSQ ²⁰	All tumour groups	18+	Oncologist permission from participating community clinical practices.	2008 paper: actively receiving more than one cycle of first or second line chem, biological or hormonal therapy.	No response information given. Sample size 361=number originally approached not provided	Not reported
PMH-MD ²¹	All tumour groups	Adults	Outpatient clinics records and Oncologist permission: recruited at site	2004 paper: oncology outpatients in follow-up clinic visits.	149 approached 92 agreed (80 completed at time 1 and time 2)	62%

Table 6 (cont.): Method of recruitment, response rates and age of samples used for quantitative studies testing the Category 1 survey tools.

Title of tool	Tumour group	Age of sample	Method of recruitment	Care point for recruitment eligibility	Number of surveys sent/returned	Response Rate
MCQ ²²	All tumour groups	Adults:	Hospital records	Phase 3: part of outpatient audit study; Phase 4: from i) outpatient audit and ii) participants in RCT	Phase 3: 285 sent, 200 return, Phase 4(i): 313 sent, 215 return, Phase 4(ii): 286 sent, 262 return.	Phase 3: 70%; Phase 4(i):69%; Phase 4(ii): 92%
Tumour group specific						
PCQ-P ²³	Prostate cancer	18+	Hospital records: mail	Diagnosed with or treated for prostate cancer in the past 2 years	1087 sent, 865 returned	80%
QUOTE-BC ¹³	Breast cancer	17+	Hospital records: mail	Experience with any type of surgery within 3-15 months before start of study.	637 sent, 299 returned	47%
CQI-BC ⁹	Malignant or benign breast disease.	18+	Claims from insurance health companies: mail	Need to have received breast care in the last 24 months.	1197 sent, 731 returned	61%
REPERES-60 ¹²	First diagnosis of invasive non-metastatic breast cancer, and at least two contacts for cancer between diagnosis and first year follow up.	Adults	Hospital records: mail	Must have been diagnosed within one year of survey	975 sent, 850 responded.	87%
IPCC ²⁴	Non-small cell lung cancer	Adults	Hospital records: mail	Newly diagnosed over a 6 month period	132 sent, 76% returned	76%
Not cancer specific						
CTM ²⁵	Not cancer specific	18+,	Hospital records: phone contact for invitation	Discharge from hospital of interest within past 6-12 weeks.	201 contacted, 200 completed	99%

How was the survey administered?

Fourteen of the 15 questionnaires listed in Table 1 were self-completed surveys. Only one questionnaire was delivered over the telephone (TCM). All other questionnaires were pencil and paper, self-completed surveys.

Characteristics of participants

Questionnaires have been administered to adult cancer patients (see Table 6). While in the main, a lower age for study participation has been specified (generally 18 years of age, few studies report an upper age limit for study participation. However all studies have criteria for the participant to be mentally competent. As most studies use medical records to identify eligible patients, hospital staff and medical notes are used to determine mental competence.

Generally these studies have not used "time since diagnosis" as an eligibility criterion. As a consequence most studies include cancer patients at various periods post diagnosis. In addition, most studies have not included stage of disease as an eligibility criterion. This means that many studies included people with early and advanced disease. While several of the studies include people with metastatic disease, none of the surveys specifically focus on palliative care experiences. One study specifically included patients receiving first line and second line chemotherapy (EORTC QLQ-INFO25). This study found no difference in the responses made on the information satisfaction scale between treatment line groups and whether patients received curative or palliative therapy.

Depending on the focus of the survey, the main eligibility criterion is the contact with the health system. For instance, the outpatient surveys require that patients have contact with the outpatient clinic within a specific timeframe (e.g. EORTC OUT-PATSAT35 eligible participants had to have received at least 3 weeks of radiotherapy). For inpatient surveys, participants had to spend a specified number of nights in hospital.

Surveys that focus on a specific tumour group have recruited patients 3-months to 2-years post diagnosis. The exception to this was the IPCC study that focused on non-small cell lung cancer.²⁴ This study recruited patients within 6 months of diagnosis. The difference in the time since diagnosis eligibility criterion for these studies may reflect the different prognoses for these diseases. In Victoria for cancers diagnosed in 2004, the 2-year survival rates for breast and prostate cancers are greater than 90%, while for lung cancer it is 20%.³⁶ Having a longer time since diagnosis eligibility criterion for breast and prostate cancer is appropriate for these diseases but would not be for lung cancer.

When considering both the eligibility criteria for studies and the time since diagnosis for approaching patients, it is important to consider the prognosis of the diseases being studied. A longer time since diagnosis for study approach will reduce the likelihood that people with cancers with a poor prognosis will participate.

Methodology recommendations

Participants eligible for the study should be 18 years and over.

Identifying patients for the study through hospital admission lists seems appropriate

Using a pencil and paper mail out survey seems appropriate

If a mail-out survey is used including at least one but preferably two reminders is needed.

There is a need to determine whether the survey is aimed at all patients regardless of treatment stage or whether the study is aimed at patients during their initial or first line treatment.

Category 2: Population-based surveys

In this section survey tools used in population-based studies that aim to assess cancer patients' experiences of care are considered. Several jurisdictions now run regular or semi regular surveys of their cancer patients to monitor the quality of care they receive from their treating hospitals. Other jurisdictions have run one off population based studies. The jurisdictions that have run regular or semi regular surveys include the United Kingdom (UK), the Australian state of NSW, the Canadian province of Ontario and parts of the United States of America (US). A one-off survey has been conducted in the Australian state of South Australia (SA). A one-off study conducted under the auspices of Cancer Australia involved data collection from several Australian states. In addition survey of cancer patients experiences of care is currently being conducted in Victoria. A survey assessing cancer patients' experiences of care has been conducted in Germany although it is unclear how often this survey has been run.

In contrast to Category 1 studies that focus on demonstrating the psychometric properties of a newly developed survey tool, most studies discussed in this section are run by a health organisation and aim to identify points of intervention to improve quality of care. Most health services that instigate these studies aim to deliver patient centred care. Patient centred care focuses on the needs and wishes of the patient rather than the needs of the health care professional or health centre. Therefore patients' judgements of the care they receive are important for the assessment of the quality of care.⁸

Several studies discussed in this section have used surveys developed by the PICKER Institute to monitor patients' experiences of care. The PICKER Institute is a not for profit organisation established to promote patient centred care. It suggests that there are eight principles of patient centred care:

- Respect for patients' values, preferences and expressed needs,
- Co-ordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends
- Transition and continuity
- Access to care

Questions in many of the PICKER Institute survey tools focus on these eight principles of care, along with other aspects considered important by patients and health care providers. The questionnaires assess experience of care rather than satisfaction, with questions asking patients to report whether an event occurred during a specific episode of care. Questionnaires are developed using a standard set of procedures that includes: literature reviews, qualitative interviews with patients and health professionals, cognitive testing of draft questionnaires and pilot testing to determine psychometric properties of the measures.

The basic PICKER Institute Inpatient survey has 40 standard items assessing seven of the eight Picker principles of care (the "access to care" principal was not included).⁸ Respondents indicate whether the event happened during their care using the scale: "yes often" "yes sometimes", "no". Responses are binary coded to indicate the presence of a "problem" or not. Early work showed that lower satisfaction ratings were associated with higher problem scores. A 15-item version of the 40- item scale has been produced and this short version has shown good internal reliability.⁸

Several organisations have worked with the PICKER Institute to produce questionnaires to monitor cancer patients' experiences of care. Three of the main jurisdictions to do this are: NSW, Australia; Ontario Canada and Germany. While the National Health Service in the United Kingdom also works with the Picker Institute to assess patients' experiences of care, they have not used a standard PICKER Inpatient or outpatient tool for their most recent survey of cancer patients' care experiences. Rather it appears the NHS worked with several organisations including PICKER Europe to develop a survey that was specific to the care of cancer patients.

Table 7 shows the jurisdictions that have developed or are developing a population based cancer patient survey monitoring system discussed in this section. The CAHPS survey is not a cancer specific tool but is included as it is developed as a survey tool and methodology to assess patients' experience of inpatient care. The aim of the information gathered by this tool is to provide consumers with information about treatment centres to help them make more informed decisions regarding the treatment centre they attend.

All studies use a patient experience survey rather than a satisfaction survey. Three of the seven jurisdictions have reported data from at least two distinct survey periods (Canada, UK and NSW).

Table 7: Population based surveys conducted in different jurisdictions, years surveys have been conducted and type of survey used.

Country	Population Assessment Systems and Tools	Type of survey	Number of items (latest version)	Years conducted
Canada	Ambulatory Oncology Patient Satisfaction Survey (AOPS) ^{37,38}	Experience of care	80	2004 2005 2006 2007
USA	Consumer Assessment of Healthcare Providers and Systems (CAHPS) ³⁹	Experience of care	27	Multiple years
UK	UK National Cancer Patient Experience Survey (NCPES) ^{40,41}	Experience of care	74	2000 2004 2010
Germany	Patient Satisfaction and Quality in Oncological Care (PASQOC) Questionnaire ⁴²	Experience of care	63	2008
Australia	CanNET ⁴³	Experience of care	65	2009
NSW, Australia	Cancer Patient Satisfaction Survey (inpatients and outpatients versions) (CPSS) ^{44,45}	Experience of care	Inpatient survey: 97 Outpatient survey: 98	2007 2008 2009
South Australia, Australia	Patient Perceptions of Cancer Care (PPCC) ⁴⁶	Experience of care	Not reported	2009
Victoria, Australia	PROSPECT study includes Cancer Critical Care Events Scale (CCCE) ⁴⁷	Experience of care	CCCE-106 items	2008/2009

Canada: Ambulatory Oncology Patient Survey (AOPS): The questionnaire used for Ontario Cancer Care is the Picker Ambulatory Oncology Patient Survey (AOPS) instrument^{37,38}. This survey was developed in Canada in 2003 and currently includes 78 closed ended questions and one or two open-ended items. The survey focuses on diagnosis and primary treatment phase of care with items covering the principles of patient centred care noted above. The sections in the survey are shown in Table 8. The survey focuses on care received in the past 6 months. While the survey instrument asks patients to indicate the clinic/hospital where different therapies were delivered, except for assessing waiting times and management of side-effects, few questions specifically address interactions with staff within each treatment department (e.g., whether there was enough privacy, whether staff treated patients with courtesy and respect etc.). Items in the questionnaire are assessed using a mix of response scales, including frequency scales (never, sometimes, usually, always), occurrence scales (yes/no or “yes completely”, “yes, somewhat”, “no”), time (<30 minutes, 30 to 60 minutes, 1 to 3 hours, >3 hours) and degree feeling informed (“very informed”, “somewhat informed”, “not at all informed”).

The survey has been run in Ontario in 2004, 2005, 2006 and 2007 and has now been run in several other provinces in Canada (e.g. British Columbia).

The tool and survey methodology has been purchased from NRC-PICKER Canada.

Cancer Quality Council of Ontario is currently reviewing the survey and its use, with the possibility of adopting new survey tools being explored.

USA: Consumer Assessments of Healthcare Providers and Systems (CAHPS): The CAHPS program commenced in 1995 in the United States with the aim of providing consumers with reliable comparative information about the quality of health plans. Since then, the program has expanded with surveys and protocols developed to assess the quality of care by hospitals, clinicians and provider groups. The CAHPS program is not specific to cancer patients but rather assesses the experience of care for any one admitted into a hospital participating in the Medicare or Medicaid program.

The CAHPS Hospital survey is a 27 item survey consisting of 22 items assessing key aspects of hospital care and 5 items eliciting information about the patients (e.g. health, education and race)³⁹. The key aspects of hospital care assessed by the 22 items are: communications with doctors; communication with nurses, responsiveness of hospital staff, cleanliness and noise level of the physical environment, pain control, communication about medicines and discharge information. The survey also includes one item rating overall hospital care and an items assessing whether the patients would recommend the hospital to others. The survey asks patients to report on their stay at a particular hospital. Most items are responded to using a frequency scale (never, sometimes, usually always), with some items using a “yes/no” response. A shortened version (16 items) of the 22 items assessing hospital care has been produced.⁴⁸ The psychometric properties of the shortened scale are adequate to very good.

Since 2008, hospitals subject to the Inpatient Prospective Payment System must collect and submit HCAHPS data to receive their annual payment.

USA: Cancer Care Outcomes Research and Surveillance Consortium (CanCORS): While not a population based monitoring study, the CANCORS project deserves a mention in this section as it is a large scale study developed to assess quality of care and associated outcomes for lung and colorectal cancer patients.⁴⁹ The National Cancer Institute and the Department of Veterans Affairs fund CanCORS. The project aims to set up a cohort of approximately 10,000 patients with newly diagnosed lung cancer or colorectal cancer, recruited from eight geographically diverse populations across the United States. Baseline and follow-up patient surveys are conducted at approximately 4 and 12 months post-diagnosis, respectively. The survey completed by participating patients collects a range of information including: treatment and treatment centres, participation in treatment decisions, quality of life, symptom management and use of supportive care services. One section of the survey assesses perceptions of quality of care received. This section contains 13 items assessing whether specific events happened during patients interaction with the health care providers with responses made on a 4-point scale from never to always.⁵⁰ The section includes items assessing delivery of information by doctors (enough, understandable, could ask questions), doctors and nurses treating the patient with courtesy and respect, how often doctors knew about treatments other doctors recommended or gave, whether knew who to go to if had questions. As the experiences of care questions do not focus on specific points in the care trajectory (that is they do not ask about interactions with health professionals at diagnosis, or specific treatments or finishing treatment etc.), they are of limited use in a survey that aims to assess quality of care throughout the cancer care trajectory. In addition the questions do not appear to be drawn from a validated scale, and there is no information on the psychometric properties of the items. Given this, the items used in this survey are not suitable for use in a survey designed to monitor the care experiences of cancer patients. This survey tool is not discussed further in this review.

United Kingdom: National Cancer Patients Experience Survey (NCPES): In 1997 the UK Government committed itself to a series of national surveys of National Health System (NHS) patients in order to monitor the performance of the NHS. The third survey in the series concerned cancer patients and was conducted in 2000⁴⁰. The aim of this survey was to assess the quality of care as seen by hospital patients diagnosed with 6 types of cancer: breast, lung, colorectal, ovarian, prostate and non-Hodgkin's lymphoma. It also aimed to provide baseline data from which changes in care as a result of the National Cancer Plan released in late 2000 could be assessed. To this end, repeat surveys of the experiences of cancer patients were conducted in 2004 and 2010⁴¹. However the 2004 survey had a substantially smaller sample size (N=4300) than both the 2000 and 2009/10 surveys (both Ns greater than 65,000). As the original aim of the survey was to contribute data to the monitoring of the NHS's performance, the study was designed on a scale large enough to enable results to be reported at a national level; the individual NHS Trust level (where results of surveys from patients treated at that particular NHS Trust are reported) and a Trust Network level (data from groups of Trusts reported).

The study's survey instrument was developed after lengthy period of work involving qualitative work with cancer patients. The survey is suitable to people with different cancers and aims to capture the care experiences at all points along the care trajectory. Both inpatient and outpatient experiences are covered in the survey.

Questions were answered using a frequency response scale (e.g. "yes always", "yes sometimes", "no" or "all the time", "some of the time", "not at all"), yes or no scales

(e.g. "Yes completely", "yes to some extent" "no but I would have liked an explanation/information etc.", "I did not need information/an explanation etc."). Responses are coded to indicate the optimal or ideal response.

As indicated, the survey has now been conducted three times with the most recent being in 2010. Several changes were made to the survey methodology for the 2010 survey, including extending the sample to include all tumour groups. Unlike the case for both the 2000 and 2004 survey, the 2010 survey specifically used the word cancer. In addition the 2010 survey included new questions both specific to cancer patients and general to all National Health System patients with these latter questions derived from the existing national patient survey. The 2010 survey only included 10 questions from the 2000 survey, making only a limited number of "over-time" comparisons possible. The inclusion of items from the national patient survey enables the experiences of cancer patients to be compared with those of general patients and is a strength of the new questionnaire.

The PICKER Institute, along with the National Centre for Social Research and the Department of Primary Health Care and General Practice are collaborating organisations with the NHS on the NHS patient surveys. Quality Health, an NHS patient survey company that conducts other patient surveys for the NHS, conducts the cancer patients' survey. The NHS Cancer Survey is run by Quality Health an NHS patient survey company that conducts other patient surveys for the NHS.

Germany: Patient Satisfaction and Quality in Oncological Care (PASQOC). The German Cancer Society and the Conference of Nurses in Oncology worked with the European arm of the PICKER Institute to redevelop an existing questionnaire to assess cancer patients' satisfaction and quality of care perceptions. Following the PICKER survey methodology, the questions used in the survey tool uses questions to assess whether specific event occurred during the patients most recent consultation. The 63-item questionnaire assesses 15 care dimensions including: physician-patient relationship, communication, nursing staff and other practice assistants, management of pain, and management of side effects⁴². Most of the response scales for items in the survey use a scale indicating whether the event occurred (e.g., "Yes always", "Yes, sometimes", "No", or "I did not need/want this (so far)"). Similar to other PICKER questionnaires, responses are recoded into a binary outcome to indicate optimal or suboptimal performance.

The Picker Institute Germany co-ordinated data collection and reported on findings from the survey.

Australia: CanNET Survey. As part of the Australian government's cancer agency's (Cancer Australia) program to link regional and metropolitan cancer services better, the Cancer Service Networks National Demonstration Program (CanNET) was developed. As part of this program Cancer Australia commissioned a survey to assess the experiences of care of people with cancer, along with the experiences of their carers/support people. The aim of the survey was to obtain baseline data on the current strengths and gaps in the delivery of cancer care as seen from the patients' point of view and to feedback this information to cancer care services in order to improve the delivery of care.

The CanNET consumer survey project was conducted in two phases, with the first involving a review of the literature, consultation with consumers and health professionals and development of a draft survey and the second involving the running and reporting of the survey. Findings from the literature review lead the researchers (Campbell Research and Consulting) to develop their own survey instrument rather than use an existing tool. The CanNET Consumer survey contains questions relating to experience of care and perceptions of care. Experience of care questions asked respondents to report on what was done in their interactions with the care team and in the treatment centre, while the perception of care questions asked respondents to report their assessments or judgements about the quality of the care delivered. The questionnaire was developed using standard procedures (review of literature, focus groups with consumers, pilot testing). The final version of the survey included 65 questions (including 3 open ended questions) for the patient and 48 questions (including 3 open ended questions) for carers/support people.⁴³

The survey is organised around four care points along the cancer care trajectory: diagnosis, receiving treatment, treatment completion and after treatment (Table 8). Several domains of care are assessed (although not all domains may be assessed at each care point) including: staff competence, information and education, environment of the treatment centre, continuity of care and psychosocial support.

The main study was conducted in 2009 and involved cancer patients from four Australian states and the Northern Territory. It is not clear whether and/or when the survey will be repeated.

Australia: New South Wales: Cancer Patients Satisfaction Survey (CPSS) The NSW Cancer Institute and the NSW Department of Health commenced a state-wide survey of cancer patients' experiences of care in 2007⁴⁴ that has been repeated in 2008⁴⁵ and 2009. Unlike the surveys conducted in Canada and Germany, the NSW cancer patients experience of care study, uses a specific survey for inpatients and another specific survey for outpatients. Both surveys are from the NRC-PICKER Institute suite of patient surveys. The outpatient survey is similar to Canada's Ambulatory Oncology Patient Survey tool. However in the NSW survey responses are generally made on a 4-point scale rather than 3-point scale and some extra questions have been added. Typical of surveys from the PICKER Institute, questions in both the inpatient and the outpatient surveys address the eight PICKER principles of patient centred care. In addition, both questionnaires contain questions addressing three supplementary dimensions that are specific to cancer patients. These areas are: i) Surgery, procedures and tests, ii) Overall attitudes and for inpatients iii) Patient Safety. The "Surgery, procedures and tests" dimension assesses communication about surgery for inpatients, while in the outpatient survey questions in this dimension assess communication about test results. The "Overall Attitude" dimension includes questions assessing the respondents overall interaction with the health care system including items assessing being treated with courtesy and collaboration of the health care staff. The "Patient Safety" dimension was included only in the inpatient survey and includes questions about aspects of health care that impacts on the patient's physical safety (e.g. nurses checked ID band before giving medications/procedure, patient felt comfortable asking questions).

Both surveys contained 96 pre-coded questions, and while both surveys included an open ended question asking patients to nominate one thing about the hospital (cancer care services in the outpatient survey) they would change, the outpatient survey also included a second open ended question asking for any other comments about their cancer journey. The Inpatient survey focused on the specific hospital experience nominated by the patient with questions covering admission, hospital staff, treatment discharge amenities and overall impressions. In contrast, the outpatient survey focused on the care received in the previous 6 months including treatment planning, actual treatment (surgery, chemotherapy, radiotherapy) symptom management, health care professionals and amenities.

Reports of findings from these surveys provide the percent of respondents giving the "ideal" response. This is termed the "Positive score".

While cancer outpatients were surveyed in a stand-alone survey, the survey of cancer inpatients was conducted as part of NSW Health's regular inpatient survey. This survey assesses the experiences of care of patients who have had at least one overnight, admitted stay in a NSW public hospital.

The survey was last conducted in 2009, however results from this 2009 survey are not yet available. In 2009, the methodology for the survey was extended to include cancer patients who received their care as an outpatient in NSW private hospitals.

The survey is conducted by the IPSOS organisation, a commercial market research firm.

Currently the NSW Cancer Institute is reviewing the survey tool used for this study.

Australia: South Australia: Patient Perceptions of Cancer Care (PPCC) The Cancer Council South Australia has conducted a one-off survey of the experiences of care of cancer patients who were admitted for at least one night at two major public teaching hospitals in South Australia between December 2004 and April 2005. The study's questionnaire was based on the UK's NCPES discussed above, modified for the South Australian context. The modified instrument was pilot tested with South Australian cancer patients to ensure the questions were relevant and comprehensible.⁴⁶

The South Australia survey included a questionnaire for carers/support people who were recruited through patients approached about participating in the study

Australia: Victoria; Patient Responses: an Ongoing Survey of People Experiencing Cancer Treatment (PROSPECT) The Cancer Council Victoria has developed a study to assess the experiences of care of cancer patients, that also assesses quality of life, unmet needs and prevalence of anxiety and depression. The study PROSPECT study commenced in 2007 with survey development work. The survey tool for this study uses a mix of existing survey tools (for instance the Hospital Anxiety and Depression scale to assess anxiety and depression, the FACT-G to assess quality of life), and an instrument developed by the researchers to assess experiences of care-the Cancer Critical Care Events survey (CCCES). The CCCES is of interest to this review. Items in the CCCES were derived from existing Australian and international guidelines for the psychosocial care of adults with cancer and assessed: information provision, emotional and psychosocial support, inclusion of family and/or friends and communication with health care professionals. The

questionnaire is for people with all forms of cancer and aims to capture care experiences along the cancer care trajectory. To this end items in the instrument are organised around critical care points including: diagnosis, treatment planning, treatment and continuity of care. The instrument has undergone cognitive testing with consumers, review by health professionals and pilot testing with a sample of 400 cancer patients.⁴⁷ The psychometric properties of the different dimensions in the scale are acceptable (Cronbach alpha's for the sections generally ranged from 0.71 to 0.80 although the Cronbach alpha for the radiotherapy section was 0.60). Further work on the CCCES has seen the survey extended to include a section on being monitored rather than actively treatment, and the addition of several new questions to the different critical points of care. The current version of the CCCES contains 106 items.

The CCCES survey assesses patients' experiences of care with questions phrased to ask if a specific event or aspect of care happened. Items are responded to on a 4-point Yes/No scale ("Yes definitely", "Yes I think so", "No I don't think so", "No definitely not"). To date answers have been coded to indicate optimal performance.

Comparison of tools used in the different jurisdictions

Table 8 presents a comparison of the care points and interactions with specific staff assessed in the surveys used in the different jurisdictions. No survey covers all areas of care or all critical care points as specified in the Patient Management Frameworks. However as the UK NCPES includes contact with GPs both before definitive diagnosis and after treatment, this survey covers the most points of care. This survey is also the only survey that includes specific questions about the three groups of medical staff patients most commonly interact with (Doctors, ward nurses and specialist nurses). However this survey includes only a minimal number of questions addressing issues of care during chemotherapy and radiotherapy. These questions include: control of side effects from treatment and control of pain and emotional support. In addition this survey only includes one question regarding care received from allied health or social services after leaving hospital. Only one survey (CanNET) includes a question asking about complaints.

Table 8: Comparison of care points specifically assessed in each of the survey tools used in the population based surveys (SA's PPCC not shown as survey based on UK.NCPES).

Sections in questionnaire	Canada AOPS^{37,38}	UK NCPES (2010)⁴¹	Australia CanNET⁴³	NSW CPSS: Inpatient^{44,45}	NSW CPSS: Outpatient^{44,45}	Victoria PROSPECT CCCES⁴⁷
GP (before or after)		✓				
Diagnostic tests	✓	✓			✓	
Diagnosis	✓	✓	✓		✓	✓
Treatment (any)			✓			
Treatment planning	✓	✓			✓	✓
Surgery	✓	✓		✓	✓	✓
Chemotherapy	✓	✓			✓	✓
Radiotherapy	✓	✓			✓	✓
Symptom management	✓		✓	✓	✓	✓
Health care providers	✓			✓	✓	✓
Doctors		✓		✓		
Specialist nurses		✓				
Ward nurses		✓		✓		
Hospital staff		✓		✓		
Support services		✓	✓		✓	✓
Going home/follow-up care		✓	✓	✓		✓
Outpatient appointments		✓				
Hospital amenities				✓	✓	
Home support		✓				
Overall	✓	✓	✓	✓	✓	✓
Complaints			✓			

Only the CAPHS survey focuses exclusively on the last hospital admission care episode. All other surveys ask about experiences of care over multiple care points in the cancer care trajectory. Only the two studies that specifically include inpatients in their samples (the UK NCPES and the NSW Inpatient CPSS) address care delivered by specific medical staff (e.g. ward nurses). The NSW Outpatient CPSS, Canada's AOPS and the CCCES of the PROSPECT study specifically address care experiences in each of the main cancer treatment modalities (surgery, chemotherapy, radiotherapy).

While the CanNET survey assesses experiences of treatment care, rather than setting a standard care episode (e.g. last contact with outpatient clinic, first chemotherapy cycle), the survey asks respondents to select one of their treatment periods and answer questions in relation to that treatment.

There is a need to determine if the areas of care included in these surveys are appropriate for patients in Victoria or whether other areas need to be included.

Conclusions and recommendations

Several jurisdictions have now undertaken large population based studies to assess the experiences of care of people being treated for cancer.

All jurisdictions use a survey tool that assesses experiences of care and this approach is recommended for the Victorian state-wide study.

All survey tools used in these population-based surveys address multiple care points and this is the recommended approach for the Victorian state-wide study.

Three of the six jurisdictions have used survey tools from the PICKER Institutes. Two of these jurisdictions are currently reviewing their survey tool.

Three jurisdictions developed tools specific to cancer patients. While no tool assesses all critical care points, the UK NCPES and the PROSPECT study's CCCES both cover a large number of care points and assess aspects of care identified as important to patients and health care providers.

As the NSW and Canadian tool are being reviewed, the CCCES and the UK NCPES should be considered as a basis for the survey tool for the Victorian state-wide study.

Consultation with Victorian cancer patients and health professionals is needed to determine if the care points and items in these surveys are appropriate and whether all areas important to the care of Victorian patients are included.

Methodology used for population-based studies

The final methodology used for a state-wide survey of the care experiences of cancer patients will be determined by a series of considerations including: the end use of the data, whether the focus of the survey is the care received at last contact with the health system or care received over the care trajectory, whether the focus is on care experiences of newly diagnosed patients or on all patients, whether the focus is on inpatients and/or outpatients and whether only public hospital care is to be examined. Other considerations include the sample of patients and whether the sample aims to represent the distribution of tumour groups in the Victorian population or whether over-sampling of some of the rarer tumours is warranted. Below we review the methodologies employed by the population-based studies to identify common approaches and differences between studies. This information can inform the design of the methodology to be employed in the Victorian state-wide study.

In this section we consider how the different studies identify and approach eligible patients, including response rates and methods used to deliver the survey to patients.

Identification of patients, recruitment and response rates

As can be seen in Table 9, most studies used hospital admittance data to identify eligible patients. A mix of sources has been used to generate the lists of inpatient and outpatient admissions. Most commonly hospitals are used to generate these lists (see Table 9). However in the NSW CPSS, the state health department generated the list of inpatients, with hospitals generating the list of outpatients. The PROSPECT study differed from this method. In this study, the population-based state cancer registry was used to identify patients. In the CanNET study, hospital admissions data was used to identify and approach patients in some participating states, while in two states, cancer registry records were used to identify and approach patients.

Studies differed in whether they included both inpatient and outpatient admissions. In the US CAHPS study and the South Australian PPCC study, eligible patients were those admitted to the hospital for at least one night. The UK NCPES included inpatient admissions and day care admissions. The NSW survey includes both inpatient and outpatient admissions. The Canadian AOPS included only those admitted for outpatient services of chemotherapy and/or radiotherapy. The German PASQOC study recruited patients from day oncology clinics and private oncology clinics. This suggests that the study includes outpatients but it is not clear whether inpatients are recruited through the private oncology clinics.

Table 9: How patients were identified for study, eligibility criteria, sample size and response rates.

	How patient identified	Eligibility	Age	Method of approach	Number of surveys sent and returned	Response rates
Canada: AOPS ^{37,38}	As detailed in report for British Columbia (BC) List developed by BC Cancer Agency. Not clear if services were involved with developing list and BC Cancer Agency confirmed eligibility.	Patients with confirmed cancer diagnosis aged 18 and over and who attended a designated health service for chemotherapy or radiotherapy or follow-up care as an outpatient within a specified period (e.g. November 2005 to May 2006). Excluded: people not having active treatment in previous 6 months, had only received inpatient services, had received oral chemotherapy and were deceased.	18+	Mail approach from the health service	BC data: In 2005//06 12,215 surveys mailed and 6974 returned (response rate ONTARIO 2007: 8291 surveys mailed and 4809 surveys returned	BC: 60% Ontario: 58%
Consumer Assessment of Healthcare Providers and Systems (CAHPS) ³⁹	Identified through hospital admissions lists	Admitted for at least one night in month Sampling procedure used Need to administer survey 48 hours to 6 weeks post discharge	18+	Mail approach by health service	Aim to get 300 completed surveys each year for each facility. Sample 900 people in a year from one treatment centre	Expect a 33% response
UK: NCPES ^{40,41}	Drawn from hospital records Trusts had to have more than 150 qualifying patients to participate in study.	2000: All patients discharged from hospital episode of care (inpatient or outpatient) between July 1999 and June 2000. 2010: All discharged from hospital between 1st January 2010 and 31st March 2010. Inpatients and outpatients included.	16+	Mail approach from the health service	2000: 92683 patients mailed questionnaires: 65337 patients responded 2010: 101064 valid surveys sent 67713 patients responded	2000: 74% 2010: 67%
Germany: PASQOC ⁴²	41 private oncology patients and 8 day hospitals in Germany	Each centre asked to identify 130 consecutive patients and the clinics obtained consent for patient to be contacted about the survey. No detail of when cancer diagnosed.	18+	Invitation to participate made in person. Questionnaire mailed subsequently.	5600 patients agreed to be contacted 4615 questionnaires returned Response rate from the number approached about participation not known	82%
Australia CanNET ⁴³	Two states: Cancer Registries; Two states and NT: hospitals	Diagnosed within past 5 years who have received treatment in the previous 6 months and do not appear on death register. Exclusion: non-reportable melanomas	18+	Mail approach either from the Cancer Registry or the Hospital	For people with cancer: 12,400 sent and 3570 returned	29%

Table 9 (cont.): How patients identified for study, eligibility criteria and numbers and response rates .

	How patient identified	Eligibility	Age	Method of approach	Number of surveys sent and returned	Response rates
NSW: CPSS ^{44,45}	Inpatient lists drawn from Health Department database, Outpatient lists generated by cancer care facilities.	Treated (inpatient or outpatient) in specific time period. Aim to mail to 480 outpatient and 100 inpatient surveys per treatment facility. When more than 480 outpatients or 100 inpatients treated, NSW Health applied a sampling procedure to select sample	18+	Mail approach from State government Health organisation	2007: 8801 cancer patients sent questionnaires, Returned surveys: Outpatients: 4129 Inpatients: 616 2008: 8500 cancer patients mailed survey. Returned surveys: Outpatients 3780 Inpatients 578	2007: 55% 2008: 53%
South Australia: PPCC ⁴⁶	Drawn from hospital records from 2 major public hospitals treating 50% of cancer patients in SA	Consecutive patients admitted for at least one night between December 2005 and April 2005. .	18+	Mailed approach by hospital. Telephone approach to complete survey	817 eligible patients 481 patients participated	59%
Victoria PROSPECT (CCCES) ⁴⁷	From Cancer Registry	Registered with the Victorian Cancer Registry within 4 months of diagnosis date	18+	Mail approach from Cancer Registry. Registry approach notifying clinician first, then patient. Researchers send questionnaire to consenting participants	Over 2008/2009 936 patients approached by Cancer Registry 429 questionnaires returned	46%

Criteria for study eligibility

The PROSPECT study recruited patients registered with the Cancer Registry within 4 months of their cancer diagnosis. The CanNET study recruited patients diagnosed with cancer in the previous five years who had received treatment at a hospital (either as an outpatient or inpatient) within the previous 6 months. It is not clear how cancer registries determined this last criterion. A quota for the different participating states was specified and a sampling procedure determined by the research company was applied to determine the sample.

Most studies utilising hospital admission lists to identify patients, aimed to recruit patients admitted for care (either as an inpatient or an outpatient) within a specified time frame (see Table 9). In the NSW CPSS participating facilities were set a recruitment target (e.g. in the NSW study, care facilities aimed to recruit 480 outpatients and 100 inpatients). Where care facilities admitted more than these numbers in the specified time period, a sampling procedure developed by the Health Department was used.

The UK NCPES only recruited from care facilities that admitted a minimum number of eligible patients (n=150) within the specified recruitment period. All eligible patients admitted during the recruitment period were approached about study participation.

The CAHPS study uses a continuous sampling procedure for data collection. That study aims to receive completed surveys from 300 eligible patients over a 12-month period. The study protocol calls for survey data to be collected from patients admitted to the treatment centre in each of the 12 months. The study estimates a 33% response rate and therefore 900 people are approached to complete the survey over a 12-month period. When treatment facilities treat more than 900 patients in a 12-month period, a sampling procedure is used to identify patients to be approached about study participation each month.

Response Rates

The response rates to the surveys range from a high of 74% for the 2000 UK NCPES to a low of 29% for the CanNET study (see Table 9). Surveys for Canada and NSW achieved response rates of around 60% and 54% respectively. The CAHPS survey response rate is around 33%. It is not clear why response rates varied so greatly. The letter of approach for the UK NCPES came from the treatment centre and this may have increased the likelihood of people responding. However as this also happens in the CAHPS survey, which achieves a much lower response rate, this cannot be the sole reason for the high response rate to the UK NCPES. Timing of receiving the survey in relation to the care event may also influence response rates. However as the highest response rate was achieved for the 2000 UK NCPES that approached people at least 6- and up to 12-months post discharge, while one of the lowest response rates was achieved for a survey that sends questionnaire within 6-weeks of discharge (CAHPS), this also cannot be the only factor influencing response rates.

A factor that may influence response rate is the study's ability to include people who speak a language other than English in their sample. Both the UK study and the NSW study made it clear that participants could complete the survey in another language. The UK study indicated that translators were available if people wanted to do the

study in another language, while the NSW study included information about the survey in 12 languages to encourage study participation.

Response rates for the studies using Cancer Registries to identify and recruit respondents varied from 46% for PROSPECT to 27%-32% for the registry component of the CanNET study. The difference in response rates might be due to the timing of the survey request in relation to the patients' diagnosis. In PROSPECT participants were approached within 6 months of their diagnosis, while the majority of people in the CanNET study were more than 6 months post diagnosis.

The CanNET report noted that a small but significant proportion of people approached about the study did not identify as having had cancer. For some of these participants, the cancer had been diagnosed several years previously and they had "forgotten" this event. Others did not recognise that their diagnosis was cancer (an example given was that melanoma was not considered a skin cancer). Approaching people several years post diagnosis might reduce the likelihood that they believe they are eligible for the study thereby reducing response rates. Unfortunately the CanNET report does not provide details of response rates by time since diagnosis.

All studies include a dedicated 1800 number for people to call if they have questions about the study or if the questionnaire raises concerns for them.

Method of survey delivery

Most questionnaires were pencil and paper surveys, mailed to participants and returned to the research organisation by return mail. The South Australian survey was delivered over the telephone. PROSPECT tested both mail and telephone delivery of the survey in their pilot study. A comparison of responses obtained from the two methodologies showed slightly more positive responses in the telephone condition compared with the mail condition. Further surveys conducted as part of the PROSPECT survey mail out a pencil and paper survey to participants.

CAHPS is the only study to provide participants with a choice of survey methods (mail, telephone, web based). To date, the majority of participants have completed a pencil and paper mailed survey. This study has also found that responses to questions administered via a telephone interview are generally more positive than responses obtained in a mailed survey.

Timing of survey—in relation to discharge from hospital

The timing of the survey in relation to the last hospital attendance differs between studies. The length of time between completing the survey and last hospital admission for the different studies is reported in Table 10. The CAPHS has the shortest time period between hospital discharge and first approach about the survey (within 6 weeks of discharge). The longest period between first approach about the survey and discharge was for the first UK survey (2000) where patients were contacted potentially between 6 to 18 months after discharge. In the 2010 UK survey patients were approached between 2-5 months post hospital discharge.

Table 10: Timing of survey in relation to hospital contact and cancer diagnosis.

	When survey completed in relation to hospital/health centre contact	When completed in relation to cancer diagnosis
Canada: AOPS ^{37,38}	IN BC Eligible patients received treatment as day patient between November 2005 and May 2006. Surveys were sent out between June and August 2006.	Not reported
USA: CAHPS ³⁹	Must be initiated within 48 hours and 6 weeks after discharge	N/A
UK: NCPES ^{40,41}	2000 survey: eligible patients in hospital between July 1999 and June 2000. Mailout began in December 2000 and went to September 2001. 2010 survey: eligible patients in hospital between January and March 2010. Surveys sent out end of May 2010—2 months after end of eligibility period.	2010 64% diagnoses within last year 26% 1 to 5 years 10% more than 5 years.
Germany: PASQOC ⁴²	While not specified, patients recruited when they contact clinic.	Not reported
Australia CanNET ⁴³	Within 6 month of last treatment at hospital	88% within the last 5 years, 9% less than a year, 51% a year ago, 13% 2 years ago, 9% three years ago.
NSW: CPSS ^{44,45}	2007: first mail-out approach four months after admission period (e.g. if February was admission period, survey sent in June). 2008: first mail-out approach three months after admission period (admission period February 2008).	2007: outpatients: diagnosed with past 12 months 39%; 1-2 years ago: 23%; 2-5 years ago: 22% 2008: outpatients: diagnosed within past 12 months: 40%; 1-2 years ago: 19%; 2-5 years ago: 25%
South Australia : PPCC ⁴⁶	Interviews conducted 4 –10 months after discharge.	Diagnosed within previous 12 months: 57%
Victoria PROSPECT (CCCES) ⁴⁷	From cancer registry Registered within 4 months of diagnosis.	Within past 6 months

Timing of survey—in relation to diagnosis of cancer

Only three reports discuss the timing of the survey in relation to when the patient was first diagnosed (Table 10). In the 2010 UK study, 64% were diagnosed with cancer in the previous 12 months while 26% were diagnosed between 1 and 5 years previously. For the CanNET study, 88% were diagnosed within the previous 5 years with 51% being diagnosed in the year preceding the survey year. In the PROSPECT study, participants were diagnosed within the previous 6 months and the survey aims to assess care received for first line treatment.

Assessing diagnosis and first line treatment experiences of patients diagnosed at different time periods may be problematic if the survey aims to determine current care experiences. If respondents have been diagnosed over different time periods, it may be appropriate to report diagnosis care experiences for different diagnosis periods.

Characteristics of participants

The characteristics of the samples surveyed in the different studies are shown in Table 11. While in the main, all studies have included all tumour groups, the 2000 UK NCPES only included six cancers: breast, colorectal, prostate, lung cancer ovarian and non-Hodgkin's lymphoma.

In most studies, the lower age for eligibility was 18 years although the UK NCPES set the lower age limit at 16 years. In general studies did not report an upper age limit, with some studies included respondents over 90 and others (e.g. PROSPECT) included respondents only up to the age of 80.

Ratios of males to females varied between the studies. Except for the CanNET study and the inpatient study for NSW, there was a greater ratio of women to men in the study samples. As more men than women develop cancer, the over-sampling of women to men may be due to several factors including women being more likely to respond to surveys and men being more likely to be diagnosed with cancers with a poor prognosis. Consideration of how to increase participation by men in population-based studies is warranted.

Time since diagnosis was reported for six of the seven studies (Table 10). In the main most participants in the studies were diagnosed in the 12-months prior to survey completion. The PROSPECT study was the only study to have all participants complete the survey within 12 months of their diagnosis.

Three studies did not report treatment stage for participants. In the studies that did report this information, one study mainly included patients having palliative care (PASQOC), in two studies most of the participants were in follow-up care (CanNET, NSW Study) and in two studies most participants were having active treatment (SA and PROSPECT). Although treatment stage varied between studies, mostly patients had finished treatment and were in follow-up care.

Table 11: Characteristics of participants in different population based studies.

	Tumour type	Age	Time since diagnosis/Time since first treated	Males: females	Stage of treatment
Canada: AOPS ^{37,38}	Patients receiving outpatient services from Cancer Care Ontario Ambulatory Clinics.	18+	Within past 6 months:12%; 6-12 months previously: 42%; more than 1 year ago:46%	Range from: males: (38%-43%); females (57%-62%)	% of patients attending outpatient clinic for treatment or follow-up not reported
UK: NCPES ^{40,41}	2000: colorectal; breast; prostate; lung; ovarion, non-Hodgkin's lymphoma, 2010 all tumour groups	16+	2000: not reported; 2010: <1yr: 64%; 1-5 years: 26%; >5 years: 10%	2000: 39%:61%; 2010: 47%:53%	2000 and 2010: not reported
PASQOC ⁴²	All tumour groups	18+	Not reported	2002: 43%: 55%; 2004: 40%: 57%	2002: Follow-up: 19%; active treatment: 20%; Palliative 58%; 2004: follow-up 16%; active treatment 24% Palliative 59%
Australia: CanNET ⁴³	All tumour groups	18 +	9% same year as survey; 51% in the previous year; (88% diagnosed within past 5 years).	54%:45%	7% only diagnosed; 20% diagnosed and receiving treatment; 73% finished treatment
NSW: CPSS ^{44,45}	All tumour groups	18+	Outpatients: 2008: diagnosed within past 12 months: 40%; 2-5 years ago: 25%	Inpatients: 2008:; 55%:45%; Outpatients: 2008: 47%: 53%	Outpatients: 2007: 69% received or had received treatment; 2008: 72% received or had received treatment
SA: PCPCC ⁴⁶	All tumour groups	18+	Diagnosed within previous 12 months: 57%	44%:56%	Treatment: 71%; diagnosis/investigation: 9%
Victoria: PROSPECT (CCCES) ⁴⁷	All tumour groups	18-80 years	On average survey completed 5 months post diagnosis	44%:56%	10% no treatment; 90% surgery; 23% radiotherapy; 38% chemotherapy: no information on % completed treatment

Summary of methodology issues

Most studies have used hospital records as the means of identifying participants for the study and have included hospital contact within a specified time period as an eligibility criterion. Only two studies have specifically recruited inpatients and outpatients, with the other studies recruiting only outpatients or not specifying type of hospital contact (e.g. PROSPECT). If the aim of a state-wide study is to assess the care received by all cancer patients both inpatients and outpatients should be included in the sampling frame for the study.

While in the main the majority of participants in the different studies were within 12 months of their diagnosis, many participants completed the study when they were more than 1 year post-diagnosis. While follow-up care is very important component of care for cancer patients, the design of the state-wide study needs to consider whether it wants to focus on the care patients experience within a specified time since diagnosis (e.g. 1 year) or not.

Few studies included information on the treatment stage of study participants. If patients are surveyed within a year of their diagnosis, determining whether they have finished treatment or not and understanding what treatments people have received will help to interpret the data.

All studies have focused on adults. While a lower age is specified in the eligibility criteria of the studies, most studies do not specify an upper age limit. With an ageing population it makes sense to include an older group of patients in the study. However if an upper age limit is not adopted for the Victorian study, including "being cognitively able to complete the survey" as an eligibility criteria may be needed.

Methodology: Conclusions and Recommendations

Similar to conclusions for Category 1 studies, identifying patients through patient records seems appropriate

There is a need to determine whether inpatients and outpatients are to be included in the study. Two population-based studies include both types of patients and this is recommended for the Victorian state-wide survey.

Most population-based studies use a mail approach to patients with the accompanying letter from the health service. This approach is recommended for the Victorian state-wide study.

If it is recommended that the state-wide survey include all cancer patients and attempt to assess care throughout the care trajectory. Assessing the stage of treatment of participants is recommended.

The study should aim to achieve a response rate over 50% and strategies to encourage participation may need to be considered. Strategies need to consider how the survey can include people who speak a language other than English.

If hospital admission lists are used to identify eligible patients, consideration of the timing of the survey in relation to discharge is needed. Most population based studies aim to approach patients regarding the survey within 3 to 6 months post hospital discharge. While approach should be made as close as possible to the timing of care, consideration of the impact of treatment on the patient is needed. Approaching patients 3 to 6 months after treatment may be optimal.

The possibility of including an eligibility criterion regarding time since diagnosis needs to be considered. While few studies limited eligibility due to time since diagnosis, most study participants were within one to two years of their diagnosis. While including a time since diagnosis eligibility criteria is recommended, this needs to be considered if hospital records are used to identify patients. If it is not possible to identify time since diagnosis through hospital records, including a question to assess this issue in the survey is needed.

When determining the "time since diagnosis" eligibility criterion, the prognosis of different cancers needs to be considered.

Feedback as a Potential use of Patient Experience Data

One of the aims of the proposed state-wide patient experience survey is to provide health service specific information that can be used to assess quality of the health care delivery and to direct interventions if improvements are needed. An additional aim of the study will be to use the data to report progress in meeting care objectives at a health services and state level. In this section the methods by which studies have reported their results is examined.

Several issues need to be considered when designing methods for feeding back survey data to health services for the purpose of improving/ensuring quality of care.⁵¹ First different groups receiving the feedback may have very different needs for the data. This not only has an impact on the presentation of the data (what is presented to whom) but also on what data is collected in the first place. For instance, health services managers may want to know whether there are differences in the care experiences of people with different cancers, necessitating presentation of data within health services by tumour group. Consequently the survey needs to collect information on the type of tumour. However others may want to know if the care experiences of cancer patients at their health service compares to the care experiences of patients treated at a different health service. This means that treatment centre data needs to be collected. Others may want to examine the care experiences of patients attending treatment centres that have different volumes of patients treated in a 6 month or 12 month period. This means that data on the case mix or throughput of cancer patients of the different health services are needed. Others may only want to know whether the care experiences of patients in their health care centre have changed over time. This focus means that data collection needs to occur on a regular basis using a standard questionnaire and standard methodology. Determining the purpose of data collection and feedback is important, as it has implications for what information is collected, sample size, who the feedback is provided to, how the information is provided and what is provided.

For feedback to influence clinical care or quality improvement initiatives, it needs to be 'actionable'.⁴⁷ The term 'actionable' has been used in the evidence implementation literature to describe clinical recommendations that are readily translated into care. Drawing on this work, Carey et al (2009)⁴⁷ have identified features of the data collection measure and the feedback process that may improve how "actionable" the feedback is. The key features identified are:

Characteristics of the questionnaire measure:

- i) *Assessing meaningful outcomes.* Recommendations for clinical care that are closely aligned with clinicians' norms and values are more likely to be acted upon.^{52,53} Similarly, measuring and reporting outcomes that are valued by patients, and are useful to the decisions made by patients, health professionals, policy makers or advocates may be perceived as more meaningful and hence may be more likely to be used.
- ii) *Assessing concrete and specific aspects of care.* Recommendations that are written in concrete and specific language are more likely to translate into clinical practice.⁵² This suggests that feedback that discusses concrete and specific aspects of care that need improving/enhancing will be more readily translated into clinical practice change. The areas that capture this specificity include:
 - a. Describing the professional group that provides the aspect of care (e.g. doctor vs nurse). For example, questions that ask: "Did you receive information from your doctor about how to manage the side effects of treatment?" is more specific than a question that asks: "Did you receive information about how to manage the side effects of treatment?"
 - b. Describing the aspect of care and the circumstances under which it occurs or should occur. For example, "Did you receive information about the side effects of treatment when you were discussing treatment options?" is more specific than the question: "Did you receive information about the side effects of treatment?"
 - c. Describing the patient group for whom the aspect of care or identified gap in care applies (e.g. "patients receiving radiotherapy for lung cancer" rather than "cancer patients").

Characteristics of the feedback report:

1. *Level of reporting.* Feedback provided at a smaller unit (e.g. treatment centre, ward) is likely to be more actionable than feedback provided at a state or national level. Providing treatment at the more aggregated levels (e.g. state) may enable treatment centres to dissociate with the data as they may not consider the data reflects their practice.
2. *Timing of feedback.* Feedback of data collected some time ago is less likely to be taken up by clinicians or health care services than feedback of data collected recently.^{54,55}
3. *Accessibility of reports.* Data presented in a long detailed report may be less readily accessed by health services and clinicians and consequently may not be attended to. Presenting data in an attractive, easily digested manner may enhance the likelihood that health services will take up the data.

While most of the authors of the Category 1 survey tools indicate that one of the aims of their survey tool is to improve the care received by cancer patients, few explicitly describe how data captured by their survey tool can be used for this purpose. As all of the Category 1 studies report on the development of a survey tool and aim to showing that the new tool is a valid and psychometrically sound tool, this may not be surprising. Future studies that use these different survey tools may provide information about how data could be used to improve cancer patients' experiences of care. However four papers explicitly discuss how the data gathered by their survey tools (the QUOTE^{chemo}, QUOTE^{BC}, QI-BC and PCP-P) can be used to improve practice and these tools and suggestions are discussed below.

The Category 2 population-based studies have an explicit aim of improving the quality of care received by cancer patients in each of their jurisdictions. The method of reporting the data from these studies is discussed below.

Below the survey instruments used in the population-based studies are discussed in terms of the questionnaire characteristics needed for "actionable" feedback.

Assessing meaningful outcomes:

All questionnaires discussed in this review (including Category 1 tools) were developed with input from patients and health professionals. While the NSW CPSS used existing PICKER Institute survey tools, the development of these tools followed standard procedures used by the PICKER Institute. The PICKER Institute procedures involve focus groups to develop items and areas that patients consider need to be assessed, expert and health professionals review of items followed by cognitive testing and pilot testing of the instrument with consumers.

All instruments reviewed here can be considered to assess areas of care that patients and health professionals consider important in the delivery of cancer care.

Assessing specific concrete events

All population-based studies use surveys that assess experiences of care and therefore are able to provide information relating to concrete and specific events that have occurred or not. In addition as most surveys ask about specific care points, they are able to determine events that happened or did not happen at specific points of care (e.g., surgery, chemotherapy, after treatment).

However most studies use surveys that do not provide information regarding the actions of specific health professional. For instance, the CanNET survey uses the generic term "health professionals" in several questions asking about delivery of information and support at diagnosis and during treatment. In addition in this survey tool, specific questions regarding interactions with the medical team relate to one member of the team (person who gave diagnosis or cancer care profession that had most contact with) rather than assessing in separate questions the experience of care delivered by different groups of health professionals. This may limit the ability of the CanNET survey to provide concrete and actionable feedback regarding the care received from specific groups of health professionals.

While the questions used in the NSW outpatient CPSS assess whether specific events occurred at different points in the care trajectory, in the main questions do not ask about care delivered from a particular health professional group (e.g. doctors or nurses). This survey tool refers to all health professionals using the term “doctors, nurses or other health care professionals involved in your care”. Similarly the Canadian AOPS does not include questions that assess the care interactions between patients and specific health professional groups at different care points. This survey uses the terms “the cancer care team”, “care providers” or “staff” to assess interactions between patients and health care providers.

The CCCES component of the PROSPECT survey contained questions assessing whether specific, concrete events happened at particular care points. The CCCES includes some questions that focus specifically on events that the doctor did or did not do. However, when not referring to a doctor, the survey uses terms like “hospital staff”, or “health professional/s” or makes no reference to a health professional in its items (e.g. in the section headed “radiotherapy”, items regarding being given information make no reference to who is providing that information). Again this may limit the survey’s ability to provide concrete and actionable feedback to specific health professional groups.

Only the 2010 UK NCPES has a set of questions assessing care received from different key health professionals, specifically hospital doctors, ward nurses, specialist nurses and GPs. While this is a strength of the survey, a limitation is that the survey tool doesn’t assess experiences of care at specific treatment points (e.g. surgery, chemotherapy or radiotherapy).

None of the surveys used in the population-based studies specifically assess services or referrals to allied health professionals such as dietitians, physiotherapists, social workers or psychologists. If understanding cancer patient experiences of care in relation to these health professionals or if it is important to understand if patients are being referred to different supportive care services, additional questions would need to be included in all patient experiences surveys discussed here.

Feedback Recommendations: survey content

As all surveys have been developed through a process of consultation with patients and health professionals, areas captured by the surveys should be important for the delivery of quality care and therefore provide appropriate targets for feedback.

All experience of care surveys assess whether specific concrete events happened and therefore provide useful data for feedback.

Few survey tools assessed care delivered from specific groups of health professions. This lack of specificity may limit how “actionable” the feedback from surveys is. There is a need to determine the level of specificity health professionals and quality managers deem important for surveys to assess and ensure surveys can address care at this level.

Characteristics of the feedback report

What is reported?

The reports from the population-based surveys discussed above generally report the percent of respondents that indicate the optimal or ideal response (e.g. a positive care event definitely happened or always happens). For instance, the NSW CPSS reports present the percentage giving the positive score and define this as the “percentage of respondents who gave “ideal” responses to a question” (NSW Report). The extent that these percentages deviate from 100% indicates the gap between current practices and “ideal” or “best” practice. An exception to this approach is the report detailing the findings from the South Australian PPCC survey. This report presents the percent of patients reporting negative experiences.

Other strategies for presenting data gathered from patient experience surveys are demonstrated in several Category 1 studies.

The two QUOTE surveys^{13,17} and the CQI-BC⁹ explicitly discuss their results in terms of using their data for quality improvement. The QUOTE family of surveys use both the importance ratings and the experience assessments of items to identify where care improvements are most needed. The QUOTE family of surveys produce Quality Impact Indices (QII) by multiplying the average importance score for an item by the percentage of participants that experienced shortcomings in performance on the item. The higher the QII score, the greater the discrepancy between performance and importance of the item and the need for improvement. The value of the QII score that suggests a need for improvement differs between the QUOTE^{chemo} scale and the QUOTE^{-BC}. While the QUOTE^{chemo} scale indicates scores of 0.30 and higher indicate the need for improvement, in the QUOTE^{-BC} the critical value is 0.40

The quality improvement scores generated from the CQI-BC use the same formula as that used for the QUOTE surveys. However unlike the QUOTE tools the CQI-BC does not specify a critical value that indicates the need for improvement. Instead the authors of the CQI-BC indicate that the higher the score the greater the need for improvement.

The Prostate Care Questionnaire-Patients (PCP-P) is also intended as a tool to provide quality improvement data to health services.²³ The PCP-P data can be presented at the overall section level (e.g. mean scores of all items in a section) or at an individual item level, where the authors recommend presenting the percentage of patients giving the optimal or ideal response. Providing both levels of data allows health services to identify overall areas of care that may need improving, along with information regarding which specific items of care need addressing.²³

Graphic representations of data

In general most reports of the population-based surveys use graphs to present the data rather than tables of percentages. The graphs generally present the proportion of respondents giving the optimal or positive response. The graphs often present data for several related items (e.g. type of information and support that was not available) together enabling a quick assessment of whether some aspects of care are more or less likely to happen.

In addition to presenting data for similar items together, several reports present data for one item or care area for different tumour groups, health services areas or other demographic characteristic in one graph (e.g. responses to the question “felt like treated as a set of symptoms” presented by tumour group). This enables a quick assessment of whether care experiences are better or worse depending on tumour group, where treated or other demographic factor.

In graphs comparing care experiences for different tumour groups or different health services, including some benchmarking data may also provide readers with a quick way to determine how care in a particular cancer or health service is performing. The report for the 2010 UK NCPES includes the average response across all cancers in their graphs reporting data for different tumour types.

Additional ways to graphically present the data collected are shown in the reports on the NSW CPSS. Data analyses conducted on the NSW data determines the correlation between individual items within a care domain (e.g. the domain of “access to care”) and ratings of “overall care received in the past 6 months”. These correlations indicate the importance of the item in an individual’s overall care assessments. Higher correlations suggest stronger associations and indicate key drivers for improving overall care assessments. The correlations are used to order the dimensions of care or items of care in the graphs, with dimensions or items at the top of the graph being more important in assessments of “overall care” than those at the bottom of the graph (Note: horizontal bar graphs are used to present data).

In addition reports on the NSW CPSS present an opportunity matrix that graphs items in terms of their correlation score (y-axis) and their positive score (percent of patients that report the optimal response for this item) (x-axis). The graph is divided into four quadrants with cut points at 75% on the x-axis and 0.4 on the y-axis. Items in the upper left quadrant (low positive score and high correlation score) indicate top priority items for intervention. Areas in the top right quadrant are considered areas of strong performance as these items are important for determining overall care assessments and have a high positive score.

The CQI-BC⁹ uses a similar strategy to present the items that need urgent attention. The method is based on the assumption that importance scores of 3 or more indicates that the item is important to consumers and that when 15% or more of patients do not indicate an ideal or optimum response, there is room for improvement. Plotting items on a grid with importance scores on the x-axis and experience scores on the y-axis provides an easy visual way to identify the items that need improvement. On this graph, the upper right quadrant indicates priority items for improvement as they are both important and have a high negative experience score while items in the upper left quadrant need improvement but are not a priority for

action (their importance is rated low). Items in the lower right quadrant indicate areas where the health provider is performing well. An example of the graphic presentation of results is shown in Figure 1. Devising ways to colour code the quadrants that indicate an aspect of care requires urgent attention and those that indicate the service is doing may increase the useability of this graphic display of results.

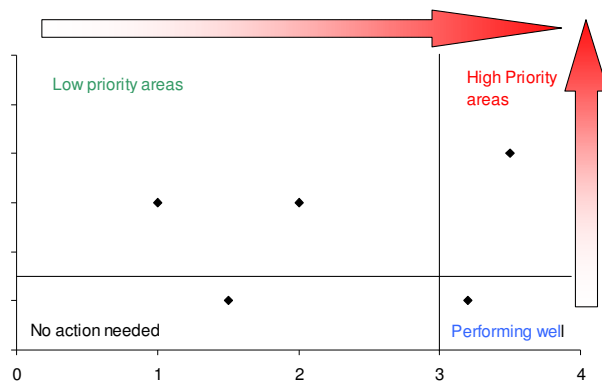


Figure 1: Example of graphic presentation of findings from the CQI-BC survey tool showing priority action areas and areas where no action is needed. Adapted from Dammon et al.⁹

Level of reporting

As indicated above, the level at which the data is reported (e.g. state, health services, hospital or ward) may influence the degree to which the feedback is actionable for specific groups. For instance provision of state level data to hospitals may have little impact on practice, as the data is not specific to the care delivered in that hospital. In addition whether the data is presented for all cancers or for specific cancers may influence the degree health professionals specialising in the care of different cancers (e.g. urologists or breast surgeons) attend to the data. In addition to tumour group, demographic factors that may be considered for reporting include age, ethnicity, and location of residence.

Table 12 shows the different demographic and health services characteristics used to report results in the different population based studies excluding the CAHPS. The reports vary considerably in presentation of the data. The reports for the UK NCPES compare the experiences of care across the largest number of demographic and health services characteristics. This study is able to do these comparisons because of its very large sample size. The other reports use a smaller number of demographic characteristics with most, but not all, comparing the results by age and tumour group.

Table 12: Reporting levels and comparison groups used in reports of population based surveys.

	Canada: AOPSS ^{37,38}	UK: NCPES ^{40,41}	Germany: PASQOC ⁴²	Australia: CanNET ⁴³	NSW: CPSS ^{44,45}	South Australia: PCPCC ⁴⁶	PROSPECT ⁴⁷
Results presentation	Overall results, health services	Trust level, age, gender, ethnicity, sexual orientation, long-term conditions, tumour type, inpatients and day case, length of time since first treatment, social deprivation, London and non-London.	Practice differences, age group, gender, tumour type, therapy type.	State cancer service networks	Inpatients and outpatients in the following categories: gender, age group, ethnicity, health status, hospital visits, tumour type.	Age group, gender, hospital and tumour group.	Tumour type;
Comparison group	Average response across areas, previous surveys	National Inpatient Survey Average response, previous survey	Previous PASQOC survey results	None	NRC Canada average Average cancer patient, average inpatient, non-cancer sites, previous surveys	NHS Cancer Patient Survey	None

Level of reporting has implications for the sample size of the study. The UK NCPES study aims to report data at an individual health trust level. To ensure estimates made at the Trust level are valid, this study must ensure a large enough sample of patients from each Health Trust is included in the national sample. Consequently the sample size for this study is substantial.

Benchmarking

As part of the development work for the Prostate Care Questionnaire-Patients (PCP-P), the acceptability of the survey tool to staff at hospitals participating in the pilot study was assessed.²³ Staff commented that the data would be most useful if their hospital data was presented against data for other comparable local hospitals or there was some other benchmarking data presented. Other work has also suggested that hospital staff find feedback data most useful when benchmarking information that compares their hospital to similar hospitals is provided.⁵⁶

Only some population-based surveys use benchmarking data when presenting results. The report on the NSW 2008 CPSS uses data from the Canadian AOPS survey as an international benchmark to which NSW results are compared. The UK 2010 NCPECS uses the average response for all patients as the benchmark when comparing data for different cancers. Cancer Ontario benchmarks treatment centre level data to the average across all centres.

Demonstrating change in patients' experience

As one of the aims of the population-based surveys is to generate improvements in the delivery of care from the patients' perspective, a key aim of the reports is to show whether patient experiences of care have changed over time. Three jurisdictions had conducted surveys of cancer patients in multiple years and therefore had the opportunity to examine change over time.

NSW: In the NSW Cancer Institute report of the 2008 survey results are compared against findings from the 2007 survey. An ↑ or ↓ arrow was used to indicate when the 2008 findings were significantly higher or lower (at the $p < .05$ level) than the 2007 findings.

Cancer Ontario: Cancer Ontario's largely reports results from their AOPS on line. The data is presented for satisfaction with overall areas of care by treatment centre and overall by year of survey. The website gives an arrow display of how patients' experiences of care is changing overall (up or down or straight) and compares this with the overall aim of overall improvement. An example of the presentation is provided below in Figure 2.



Figure 2: The graphic used by Cancer Ontario to indicate what change in the care experience Cancer Ontario is aiming for, and actual change in patients' reports between survey years.

UK: Due to differences in the questionnaire and samples in the 2010 and 2000 UK NCPES, comparisons to previous years were limited. Only 10 items in the 2010 UK NCPES were included in the 2000 NCPES. As the 2000 survey only included patients with non-Hodgkin's lymphoma and lung, breast, colorectal, prostate and ovarian cancers comparisons with 2010 data from these 10 items is presented separately for participants with these six cancers and for all other tumour types.

In addition to this set of comparisons the 2010 UK report also compares results for cancer patients with findings from the 2009 national inpatient survey on the set of questions that were derived from that survey. Seventeen items in the NCPES were similar to items in the inpatient survey. Data were presented in table form with the proportion of patients reporting the ideal or optimum response to each item shown. The results show that in general cancer patients' inpatient experiences are more positive than those of inpatients in general.

Timing of the release of the report in relation to data collection

While all population based studies would endeavour to release the data back to their stakeholders as soon as possible, studies have not specifically discussed this. The provision of a comprehensive state-wide or national report such as those used to present the findings from the UK NCEPS, CanNET and the NSW CPSS, can take a substantial amount of time to produce. For instance, while participants in the NSW CPSS attended hospitals in February 2008, the state-wide report was released in July 2009. While this time lag may be inevitable due to the time needed for data collection, data processing and report production, it does reduce the timelines of the data for quality improvement. The report on the 2010 UK NCPES was released nine months after the end of their patient eligibility period. The shorter period for report production helps to increase the timeliness of the data.

Determining of a time period for releasing report that takes into consideration the time needed for data collection, processing and reporting and the needs of health services to receive timely data is needed.

Feedback: Conclusions and Recommendations

It is important to determine the reporting levels needed as this has important implications for the sample size needed for the state-wide survey. Reporting levels to be considered include but are not limited to: organisational unit to be reported (e.g., hospital, ward, health area, state), tumour group, and regional and metropolitan.

Most reports present the percentage of participants giving the ideal or optimal response. This approach shows the extent to which current practice meets best practice.

Several reports attempt to highlight areas that are most important to patients. This approach highlights areas of care that can be targeted for improvement that may have most impact on patients care experiences. This approach is recommended for feeding back results from the Victorian state-wide survey.

Providing a visual representation of results, including a visual representation of areas of care that need priority action is recommended. The method of achieving this may depend on the type of data collected by the survey tool selected for the survey, but methods employed by for the NSW CPSS or the Category 1 survey tool CQI-BC provide starting points for consideration of this issue.

Including some benchmarking data in the report for comparison purposes is recommended. Benchmarking data might be the average performance across the state, international comparisons or goals set by appropriate authorities.

As one of the aims of the state-wide study is to monitor the care experiences of cancer patients, the report will need to consider how best to present comparison of data obtained in different survey years. A visual representation of change has been used in several studies (e.g. up or down arrows) and this is recommended for the report of the Victorian state-wide survey.

The interval between surveys needs to be considered. Factors that need to be considered when determining the interval for repeat surveys include resources and time needed for surveying; as well as the time services need to implement improvement interventions.

Timeliness of the release of the report from the survey needs to be considered. While a realistic timeline is needed (giving consideration of the time needed for data collection, data processing and reporting) reports need to be released as soon as practical. Consultation with health professionals and quality improvement managers regarding their preferred timelines for receiving the feedback is needed. Developing a process of reporting that can accommodate the needs of health care services and data collection/reporting agencies is needed.

REFERENCES

1. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001; 10 (1): 19-28.
2. Oliver A, Greenberg CC. Measuring outcomes in oncology treatment: the importance of patient-centered outcomes. *The Surgical Clinics of North America* 2009; 89 (1): 17-25, vii.
3. Stewart M. Towards a global definition of patient centred care. *BMJ* 2001; 322 (7284): 444-445.
4. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000; 88 (1): 226-237.
5. Sofaer S, Firminger K. Patient perceptions of the quality of health services. *Annual Review of Public Health* 2005; 26: 513-559.
6. Williams SJ, Calnan M. Convergence and divergence: assessing criteria of consumer satisfaction across general practice, dental and hospital care settings. *Social Science & Medicine* 1991; 33 (6): 707-716.
7. Pearse J. *Review of patient satisfaction and experience surveys conducted for public hospitals in Australia*. Health Policy Analysis: 2005.
8. Jenkinson C, Coulter A, Bruster S, Richards N, Chandola T. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Quality & Safety in Health Care* 2002; 11 (4): 335-339.
9. Damman OC, Hendriks M, Sixma HJ. Towards more patient centred healthcare: A new Consumer Quality Index instrument to assess patients' experiences with breast care. *European Journal of Cancer* 2009; 45 (9): 1569-1577.
10. Bonevski B, Sanson-Fisher R, Girgis A, Burton L, Cook P, Boyes A. Evaluation of an instrument to assess the needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000; 88 (1): 217-225.
11. Love A, Liversage L. *The Experience of the cancer journey for patients and their carers in the Grampians Region*. Grampians Integrated Cancer Services: Melbourne, Australia, December 2011.
12. Defossez G, Mathoulin-Pelissier S, Ingrand I, Gasquet I, Sifer-Riviere L, Ingrand P, Salamon R, Migeot V. Satisfaction with care among patients with non-metastatic breast cancer: development and first steps of validation of the REPERES-60 questionnaire. *Annals of Oncology* 2007; 7: 129.

13. de Kok M, Sixma HJ, van der Weijden T, Kessels AG, Dirksen CD, Spijkers KF, van de Velde CJ, Roukema JA, van der Ent FW, Finaly-Marais C, von Meyenfeldt MF. A patient-centred instrument for assessment of quality of breast cancer care: results of a pilot questionnaire. *Quality & Safety in Health Care* 2010; 19 (6): e40.
14. Bredart A, Bottomley A, Blazeby JM, Conroy T, Coens C, D'Haese S, Chie WC, Hammerlid E, Arraras JI, Efficace F, Rodary C, Schraub S, Costantini M, Costantini A, Joly F, Sezer O, Razavi D, Mehlitz M, Bielska-Lasota M, Aaronson NK. An international prospective study of the EORTC cancer inpatient satisfaction with care measure (EORTC IN-PATSAT32). *European Journal of Cancer* 2005; 41 (14): 2120-2131.
15. Bredart A, Mignot V, Rousseau A, Dolbeault S, Beauloye N, Adam V, Elie C, Leonard I, Asselain B, Conroy T. Validation of the EORTC QLQ-SAT32 cancer inpatient satisfaction questionnaire by self- versus interview-assessment comparison. *Patient Education and Counseling* 2004; 54 (2): 207-212.
16. Arraras JI, Kuljanic-Vlasic K, Bjordal K, Yun YH, Efficace F, Holzner B, Mills J, Greimel E, Krauss O, Velikova G. EORTC QLQ-INFO26: a questionnaire to assess information given to cancer patients a preliminary analysis in eight countries. *Psychooncology* 2007; 16 (3): 249-254.
17. van Weert JC, Jansen J, de Bruijn GJ, Noordman J, van Dulmen S, Bensing JM. QUOTEchemo: a patient-centred instrument to measure quality of communication preceding chemotherapy treatment through the patient's eyes. *European Journal of Cancer* 2009; 45 (17): 2967-2976.
18. Liekweg A, Eckhardt M, Taylor SC, Erdfelder E, Jaehde U. Psychometric assessment and application of a questionnaire measuring patient: satisfaction with information on cancer treatment. *Pharmacy World & Science* 2005; 27 (2): 96-103.
19. Abetz L, Coombs JH, Keininger DL, Earle CC, Wade C, Bury-Maynard D, Copley-Merriman K, Hsu MA. Development of the cancer therapy satisfaction questionnaire: item generation and content validity testing. *Value Health* 2005; 8 Suppl 1: S41-53.
20. Llewellyn CD, Horne R, McGurk M, Weinman J. Development and preliminary validation of a new measure to assess satisfaction with information among head and neck cancer patients: the satisfaction with cancer information profile (SCIP). *Head & Neck* 2006; 28 (6): 540-548.
21. Loblaw DA, Bezjak A, Bunston T. Development and testing of a visit-specific patient satisfaction questionnaire: the Princess Margaret Hospital Satisfaction With Doctor Questionnaire. *Journal of Clinical Oncology* 1999; 17 (6): 1931-1938.
22. Harley C, Adams J, Booth L, Selby P, Brown J, Velikova G. Patient experiences of continuity of cancer care: development of a new medical care questionnaire (MCQ) for oncology outpatients. *Value Health* 2009; 12 (8): 1180-1186.

23. Tarrant C, Baker R, Colman AM, Sinfield P, Agarwal S, Mellon JK, Steward W, Kockelbergh R. The prostate care questionnaire for patients (PCQ-P): reliability, validity and acceptability. *BMC Health Services Research* 2009; 9: 199.
24. Ouwens M, Hermens R, Hulscher M, Vonk-Okhuijsen S, Tjan-Heijnen V, Termeer R, Marres H, Wollersheim H, Grol R. Development of indicators for patient-centred cancer care. *Support Care Cancer* 2009.
25. Coleman EA, Smith JD, Frank JC, Eilertsen TB, Thiare JN, Kramer AM. Development and testing of a measure designed to assess the quality of care transitions. *International Journal of Integrated Care* 2002; 2: e02.
26. Coleman EA, Mahoney E, Parry C. Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Medical Care* 2005; 43 (3): 246-255.
27. Arraras JI, Rico M, Vila M, Chicata V, Asin G, Martinez M, Hernandez B, Arias F, Martinez E. The EORTC cancer outpatient satisfaction with care questionnaire in ambulatory radiotherapy: EORTC OUT-PATSAT35 RT. Validation study for Spanish patients. *Psychooncology* 2010; 19 (6): 657-664.
28. Bredart A, Razavi D, Robertson C, Didier F, Scaffidi E, de Haes JC. A comprehensive assessment of satisfaction with care: preliminary psychometric analysis in an oncology institute in Italy. *Annals of Oncology* 1999; 10 (7): 839-846.
29. Hjorleifsdottir E, Hallberg IR, Gunnarsdottir ED. Satisfaction with care in oncology outpatient clinics: psychometric characteristics of the Icelandic EORTC IN-PATSAT32 version. *Journal of Clinical Nursing* 2010; 19 (13-14): 1784-1794.
30. Jayasekara H, Rajapaksa L, Bredart A. Psychometric evaluation of the European Organization for Research and Treatment of Cancer in-patient satisfaction with care questionnaire ('Sinhala' version) for use in a South-Asian setting. *International Journal for Quality in Health Care* 2008; 20 (3): 221-226.
31. Arraras JI, Vera R, Martinez M, Hernandez B, Lainez N, Rico M, Vila M, Chicata V, Asin G. The EORTC cancer in-patient satisfaction with care questionnaire: EORTC IN-PATSAT32 Validation study for Spanish patients. *Clinical & Translational Oncology* 2009; 11 (4): 237-242.
32. Trask PC, Tellefsen C, Espindle D, Getter C, Hsu MA. Psychometric validation of the cancer therapy satisfaction questionnaire. *Value Health* 2008; 11 (4): 669-679.
33. Horne R, Hankins M, Jenkins R. The Satisfaction with Information about Medicines Scale (SIMS): a new measurement tool for audit and research. *Quality in Health Care* 2001; 10 (3): 135-140.

34. Loblaw DA, Bezjak A, Singh PM, Gotowiec A, Joubert D, Mah K, Devins GM. Psychometric refinement of an outpatient, visit-specific satisfaction with doctor questionnaire. *Psychooncology* 2004; 13 (4): 223-234.
35. Parry C, Mahoney E, Chalmers SA, Coleman EA. Assessing the quality of transitional care: further applications of the care transitions measure. *Medical Care* 2008; 46 (3): 317-322.
36. English D, Farrugia H, Thursfield V, Change P, Giles G. *Cancer Survival Victoria 2007. Estimates of survival in 2004 (and comparisons with earlier periods)*. The Cancer Council Victoria: Melbourne, Australia, April 2007. Available from [http://www.cancervic.org.au/media/cancer-statistics-media/cancer survival in victoria/](http://www.cancervic.org.au/media/cancer-statistics-media/cancer%20survival%20in%20victoria/).
37. Watson DE, Mooney D, Peterson S. *Patient experiences with ambulatory cancer care in British Columbia, 2005/06 [electronic resource]*. UBC Centre for Health Services and Policy Research, March 2007. Available from [http://www.health.gov.bc.ca/library/publications/year/2007/OncologySurvey/UBC OncologyReport.pdf](http://www.health.gov.bc.ca/library/publications/year/2007/OncologySurvey/UBC%20OncologyReport.pdf).
38. Cancer Care Ontario. *Cancer Care Ontario: Action Cancer Ontario*. 2011. Retrieved from <http://www.cancercare.on.ca/>.
39. Davies E, Shaller D, Edgman-Levitan S, Safran DG, Oftedahl G, Sakowski J, Cleary PD. Evaluating the use of a modified CAHPS survey to support improvements in patient-centred care: lessons from a quality improvement collaborative. *Health Expect* 2008; 11 (2): 160-176.
40. Airey C, Becher H, Erens B, Fuller E. *Cancer: National Overview 1999/2000. NHS cancer plan: A baseline survey*. Department of Health, NHS: UK2002.
41. UK Department of Health. *National Cancer Patient Experience Survey Programme – 2010 National Survey Report*. Department of Health, NHS: UK2010.
42. Kleeberg UR, Feyer P, Gunther W, Behrens M. Patient satisfaction in outpatient cancer care: a prospective survey using The PASQOC questionnaire. *Support Care Cancer* 2008; 16 (8): 947-954.
43. CanNET. *Assessment of Cancer Care Perceptions and Experiences of People Affected by Cancer*. Cancer Australia: Melbourne, Australia, August 2010.
44. Heading G, Mallock N, Sinclair S, Bishop J. *Cancer Patient Satisfaction Survey 2007, Interim Report*. Cancer Institute NSW: Sydney, Australia2008.
45. Heading G, Mallock N, Sinclair S, Bishop J. *New South Wales Cancer Patient Satisfaction Survey 2008*. Cancer Institute NSW: Sydney, Australia2009.
46. Beckmann KR, Olver IN, Young GP, Roder DM, Foreman LM, Wilson B. Patient and carer perceptions of cancer care in South Australia. *Australian Health Review* 2009; 33 (4): 645-655.

47. Carey M, Ieropoli S, White V. *The PROSPECT program (Patient responses: An ongoing survey of people experiencing cancer treatment). Pilot Study*. Prepared for: CanNET Victoria. Centre for Behavioural Research in Cancer, The Cancer Council Victoria: Melbourne, Australia, August 2009.
48. Keller S, O'Malley AJ, Hays RD, Matthew RA, Zaslavsky AM, Hepner KA, Cleary PD. Methods used to streamline the CAHPS Hospital Survey. *Health Services Research* 2005; 40 (6 Pt 2): 2057-2077.
49. Malin JL, Ko C, Ayanian JZ, Harrington D, Nerenz DR, Kahn KL, Ganther-Urmie J, Catalano PJ, Zaslavsky AM, Wallace RB, Guadagnoli E, Arora NK, Roudier MD, Ganz PA. Understanding cancer patients' experience and outcomes: development and pilot study of the Cancer Care Outcomes Research and Surveillance patient survey. *Support Care Cancer* 2006; 14 (8): 837-848.
50. Ayanian JZ, Zaslavsky AM, Arora NK, Kahn KL, Malin JL, Ganz PA, van Ryn M, Hornbrook MC, Kiefe CI, He Y, Urmie JM, Weeks JC, Harrington DP. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. *Journal of Clinical Oncology* 2010; 28 (27): 4154-4161.
51. Madden PB, Davies EA. Reporting cancer patients' experiences of care for quality improvement: analysis of 2000 and 2004 survey results for South East England. *Journal of Evaluation in Clinical Practice* 2010; 16 (4): 776-783.
52. Grol R, Dalhuijsen J, Thomas S, Veld C, Rutten G, Mokkink H. Attributes of clinical guidelines that influence use of guidelines in general practice: observational study. *BMJ* 1998; 317 (7162): 858-861.
53. Foy R, MacLennan G, Grimshaw J, Penney G, Campbell M, Grol R. Attributes of clinical recommendations that influence change in practice following audit and feedback. *Journal of Clinical Epidemiology* 2002; 55 (7): 717-722.
54. Davis DA, Taylor-Vaisey A. Translating guidelines into practice. A systematic review of theoretic concepts, practical experience and research evidence in the adoption of clinical practice guidelines. *Canadian Medical Association Journal* 1997; 157 (4): 408-416.
55. van der Weijden T, Grol R. Feedback and reminders Edinburgh. In: Grol R, Wensing M, Eccles M, (Eds). *Improving patient care: the implementation of change in clinical practice*. New York: Elsevier Butterworth Heinemann, 2005, pp. 290.Ch 11.
56. Draper M, Cohen P, Buchan H. Seeking consumer views: what use are results of hospital patient satisfaction surveys? *International Journal for Quality in Health Care* 2001; 13 (6): 463-468.