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A Delphi study to develop indicators of cancer patient experience for quality improvement

Abstract

Purpose: The purpose of this study was to develop prioritised indicators to measure cancer patient experience and thus guide quality improvement in the delivery of patient care.

Methods: A Delphi study, consisting of two surveys and three workshops, was employed to gather expert opinions on the most important indicators to measure. Survey participants were 149 health professionals, academics/technical experts and consumers. The first survey was based on a literature review which identified 105 elements of care within 14 domains of patient experience. These were rated on a 7-point Likert scale, with '1' representing high importance. Elements with mean ratings between 1.0 and 2.0 were retained for the second survey. The 43 least-important elements were omitted, four elements were revised and nine new elements added. Consensus was defined as at least 70% of participants rating an element '1' or '2'. Multivariate and cluster analyses were used to develop 20 draft indicators, which were presented to 51 experts to refine and prioritise at the three workshops.

Results: All elements in the second survey were rated '1' or '2' by 81% of participants. Workshop participants agreed strongly on the four most important indicators: coordinated care, access to care, timeliness of the first treatment, and communication. Other indicators considered highly important were follow-up care for survivors; timeliness of diagnosis; information relating to side effects, pain and medication; comprehensibility of information provided to patients; and needs assessment.

Conclusions: Experts identified priorities with a high level of consensus, providing a rigorous foundation for developing prioritised indicators of quality in cancer patient experience.

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PATIENT EXPERIENCE INDICATORS

A DELPHI STUDY TO DEVELOP INDICATORS OF CANCER PATIENT EXPERIENCE FOR QUALITY IMPROVEMENT

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Keywords

Patient experience; quality indicators; quality improvement; Delphi; cancer

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A DELPHI STUDY TO DEVELOP INDICATORS OF CANCER PATIENT EXPERIENCE FOR QUALITY IMPROVEMENT

Patient experience indicators in cancer care allow health practitioners to identify opportunities for positive change in services and systems, leading to better cancer outcomes [1]. They can be used to benchmark performance of cancer services at state, national and international levels. The development of appropriate and acceptable cancer patient experience indicators should be informed by what matters to patients and engage health care providers and technical experts [1]. This article reports on the results of a structured consultation process using the Delphi technique to develop prioritised indicators of cancer patient experience. The study was commissioned by the Cancer Institute of New South Wales as an important step in developing systems for monitoring and improving the delivery of health services to cancer patients.

A literature review was conducted to identify domains (priority areas) in which cancer patient experience indicators are relevant. This was an important first step because patient experience is a broad concept that encompasses many aspects of the organisation and delivery of health care [2]. Indicators may be generic and apply to patients' experiences irrespective of their reasons for requiring health care, as in the principles of the Picker Institute [3], or specific to a condition and treatment setting, such as a cancer patient's experience of radiotherapy. In some clinical fields there are many well-defined indicators of care quality [4, 5]; however, a recent review identified relatively few published indicators of cancer care [6, 7].

A justification for the specific domains chosen for the Delphi study is provided by current work in Scotland, England and Canada. For example, the National Health Service (NHS), Scotland, aims to develop "cancer-specific ... evidence-based indicators ... underpinned by patient experiences" in order to focus quality improvement activity on the

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areas that will have most impact on survival and effective care delivery [8, p.3]. In England, the NHS National Cancer Patient Experience Survey (CPES) measures the experience of cancer patients across nine domains, including access, care coordination, communication and emotional support [9]. This tool has recently been adapted in Australia by the Victorian Comprehensive Cancer Centre [10]. Performance of the Canadian cancer control system is measured by indicators along the continuum of cancer control: prevention, screening, diagnosis, treatment and person-centred perspective [11].

The Delphi technique has been employed to develop indicators for the quality of cancer care in the Netherlands [12, 13], Taiwan [14], Japan [15] and Greece [16, 17]. These studies used rating scales to develop a range of indicators within the following domains:

- Communication [13, 16]
- Physical support, symptom control [13, 15, 16]
- Psychosocial support and care [13, 15, 16]
- Patient-centred care, including multi-disciplinary teams [14]; shared decision making [15]; and care coordination, timely diagnosis and treatment, and support for self-management [13]
- Equity of access for patients from regional areas [16];
- Monitoring and surveillance during remission [13];
- Care for families of cancer patients [15].

The aim of this study was to develop prioritised indicators of cancer patient experience for use in guiding service improvement. Patient experience was envisaged as covering most phases of the patient pathway (assessment, diagnosis and treatment), most care settings (primary care, hospital inpatient and outpatient facilities, sub-acute facilities and community services) and all tumour groups. In order to fulfil the aim of the study it was

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imperative to obtain a diverse range of expert views. While most commonly an expert will have a relevant professional or academic qualification, consumers may be considered experts because of their lived experience. The importance of involving consumers in the Delphi process has been identified [18]. Compared with providers, consumers may have different priorities [17]. The inclusion of patients and carers was therefore seen as appropriate and was consistent with two previous Delphi studies that developed cancer care indicators [13, 16, 17].

METHODS

Design

The Delphi technique employs a series of surveys, interspersed with feedback to participants, to obtain anonymous opinions from experts. There are no universally accepted requirements or guidelines that specify, for example, the number of rounds or the definition of consensus [4]. Nevertheless, the four commonly accepted characteristics of the Delphi method have been incorporated into the current study: anonymity; iteration; controlled feedback; and statistical analysis of the group response [19].

Participants

A purposive, criterion-based sampling approach was adopted. The participants' primary criterion was their specialist knowledge, gained through experience or qualifications, demonstrating interest in cancer patient experience and/or patient experience measurement. Three categories of experts were sought: health care professionals, consumers and academics or technical experts. Experts were identified through professional networks of team members, examination of the authorship of key literature, and internet searching. Consumer

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representation was obtained through participation of key consumer groups within New South Wales and Australia.

At the end of the Round 2 survey, respondents were asked to indicate their interest in participating in further consultation activities. Those who expressed interest were invited to a consultation workshop.

Materials

The Round 1 questionnaire was based on a literature scan, which drew on previous reviews [6, 7, 20], and patient experience measures and surveys used in Australia and overseas. This identified 14 domains (Table 1) and 105 associated elements (specific aspects) of cancer patient experience.

The questionnaire presented elements within each domain. Participants were asked how important it was *to measure* each element or domain. This instruction was repeated at the beginning of each section to remind participants that they should consider whether measuring an aspect of care could be useful to inform quality improvement activities.

Each element within each domain was rated on a Likert-type scale from 1 *High importance* to 7 *Low importance*. After rating all elements in a domain, participants were asked to select the most important element. They were asked to comment and whether other (new) elements should be included in that domain. After rating all 105 elements, they were presented with the list of 14 domains and asked to rate them on the same seven-point scale used for the elements. Finally, the list of 14 domains was presented again, and participants were asked to select the seven most important domains and rank them in order of importance. The procedure of rating and ranking the domains provided further insights into patterns within the data set that revealed participants' priorities, beyond those obtained by looking at elements in isolation.

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The questionnaire was modified following analysis of the Round 1 data. Based on mean ratings, 43 least important elements were eliminated. The aim of revising the questionnaire was to reduce participant burden and encourage consensus. Elements that had a mean rating of 2 or less in Round 1 were included in the Round 2 questionnaire. The cut point for inclusion of elements for Round 2 was chosen because a mean score of 2 or less indicated that most participants had rated the element as very important (lower scores = greater importance). The percentage of participants who rated the elements as highly important (i.e., a rating of '1' or '2') was also considered. The qualitative feedback from Round 1 highlighted aspects of patient care that were not adequately covered, leading to the revision of four elements and the creation of nine new elements. The Round 2 questionnaire included 71 elements within the same 14 domains. The order in which domains were presented was reversed to control for order effects and respondent fatigue. The questionnaires were piloted to ensure the task was clear and participant burden was minimised.

Procedure

The Delphi questionnaires were developed and managed using REDCap (Research Electronic Data Capture), a web-based application [21]. Robust security and access controls were in place. The study was approved by the university's human research ethics committee. After approval, invitations were emailed to experts from the Deputy CEO of the commissioning organisation; 183 invitations for Round 1 were delivered successfully.

In Round 2, respondents were given: (1) their own Round 1 rating for each element or domain (inserted automatically via a computerised process to protect confidentiality); (2) the percentage of respondents who gave the element or domain a rating of 1; and (3) the group response in Round 1: mean and standard deviation.

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The draft indicators derived from these processes were then assessed and prioritised by three expert groups in workshops (N=51). Participants were given 20 cards, each representing an indicator. They were asked to select the 10 indicators that were most important to measure and to sort them in order of priority, and this individual information was then transferred onto forms for analysis. The group's priorities were then discussed.

Data analysis

Questionnaire responses were exported from REDCap into an Excel spreadsheet and SPSS for statistical analysis. Consensus (i.e., importance and agreement) was defined by examining the data distribution, mean, median and percent of respondents rating an element as highly important. To be considered important, a domain element had to obtain a mean rating of between 1.0 and 2.0. The percentage of participants who nominated an element as most important within a domain was also examined. For the domains, the ratings and the rankings were considered when determining relative importance. The level of agreement was defined as the percentage of participants who rated an element (or domain) as '1' or '2'. At least 70% agreement was required for consensus.

Hierarchical cluster analysis was used to investigate the structure of the ratings data as a guide to reducing the large set of elements to a smaller set of indicators. Each round of the Delphi survey was analysed separately. The data source for the cluster analysis was a similarity matrix comprising the Pearson correlations among the element ratings. Correlation coefficients are frequently used as similarity measures for cluster analysis in the social sciences [22]. Hierarchical cluster analysis was chosen because it assumes that items are nested within increasingly abstract categories. The technique does not generate fit statistics as a range of solutions are possible. Principal components and scale analyses were also conducted in developing measurement tools for summary indicators.

RESULTS

Of the 183 invitations delivered for the Round 1 survey, 158 individuals responded (86%) with 149 usable responses (81%). Only respondents who had been included in Round 1 analysis were invited to Round 2. A total of 112/149 surveys were returned (75%) and all were included in the analysis. A description of the Delphi respondents is provided in Table 2.

Element ratings and ‘most important’ elements

Elements that received the highest mean ratings in Round 2 are presented in Table 3, listed by domain. All Round 2 elements were rated as ‘1’ or ‘2’ by 81% of participants, indicating both high importance and high agreement. Standard deviations of mean ratings could be compared across the two Delphi rounds for 58 elements. For 52 elements, the standard deviation decreased, providing another indication of movement towards consensus.

Domain ratings and rankings

Table 4 presents the ratings of the 14 domains of patient experience in both rounds of the Delphi survey. Domains are listed in order of importance, with those receiving the lowest mean ratings (highest importance) in Round 2 presented first. The percentage of participants who gave a rating of either ‘1’ or ‘2’ (highly important) is shown for each domain. At least 90% of participants gave these ratings for the top six domains in Round 2, a marked change from Round 1 when opinions were more varied. Table 4 also presents the percentage of participants who ranked each domain in their ‘top 2’ (i.e., ranked either first or second). The Round 2 domain rankings and ratings were highly consistent despite the constraints imposed by the forced-choice format of the ranking task. In both tasks the participants identified the same three domains – coordinated care, timeliness of care and communication by doctors – as

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the most important for measuring patient experience. Technical expertise of health professionals and comprehensive information provided to patients were also considered highly important in both ratings and rankings.

Structure of the data

In the cluster analysis, solutions offering around 20 clusters were selected as the original project brief specified 20 prioritised indicators. All solutions included unattached items that had not yet joined clusters. Solutions from the two surveys were consistent. For domains in which multiple important elements were identified, a procedure for developing summary indicators was adopted, based on previous work [8]. Other elements that remained unattached to clusters across the two rounds were marked out as possible stand-alone indicators. This resulted in a list of 20 draft indicators.

Final indicators

Four indicators were strongly endorsed by the workshop participants: *coordinated care; access to care; timeliness of first treatment; and communication* (Table 5). These indicators were considered the most important based on both the percentage of participants including them in the top ten and the mean rank data. Figure 1 shows that these indicators were most often ranked first, second or third by workshop participants.

There were another eight indicators with moderate to higher levels of endorsement (45-63%): *follow-up care/ survivorship, timeliness of diagnosis, aspects of information provision, needs assessment, shared decision making, and psychosocial care*. At least half the participants included nearly all of these indicators in their top ten. The remaining 12 indicators had lower rates of endorsement (39% or less) by the workshop participants and these may be considered of lesser importance.

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The workshop rankings established a priority order for the final suite of indicators (Table 5). The wording of the indicators was refined during the workshops and through subsequent discussions with the commissioning organisation.

DISCUSSION

This project identified cancer patient experience indicators that, if monitored regularly, could guide service improvement and practice change. Expert participants in the Delphi process were presented with elements and domains of cancer patient experience derived from the literature. They were asked to judge which were the most important to measure. Findings from the two rounds of Delphi surveys were used to gauge the experts' priorities and to understand relationships in the data so that the large set of elements and domains could be reduced to a list of 20 draft indicators as required in the project brief. Participants in three workshops then ranked the draft indicators and their feedback was incorporated into the final set of prioritised indicators of cancer patient experiences.

Cancer patient experiences were defined broadly. The resulting indicators are therefore generic and have wide application across a range of cancer services. Although there have been several published Delphi studies on cancer care quality indicators, one was specific to breast cancer [14] and another focused on end-of-life care [15]. Delphi research on cancer services in Greece focused on identifying areas in which improvement was most needed [16, 17] whereas in the Netherlands the focus was on patient-centred cancer care [12, 13].

Despite differences in emphasis and variations in the way the Delphi technique was applied, there are similarities between the sets of indicators produced by those studies and the current research. Most highlighted the importance of patient-centred care, including care coordination, opportunities for the patient to participate in care planning and decision making, and needs assessment to support multidisciplinary care and referral to specialist services where required. Psychosocial support appeared consistently across the lists of

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indicators. Other important aspects of patient experience identified in the current research were found in some of the previous Delphi studies. These included indicators relating to communication, timeliness of diagnosis and treatment, access to care, and follow-up care for cancer survivors. Some of these indicators, notably communication and information provision, are supported by other recent work such as the development of generic cancer care indicators for the NHS Scotland [8].

One sensitive methodological issue with the Delphi method is the definition of consensus. The investigators must decide how agreement among participants will be measured and, if the agreement rate is used, what cut-off will be used to define consensus. The method used to define consensus varied across the previous Delphi studies reviewed for this research. With each additional survey round, consensus is expected to increase; however, the potential for bias increases with respondent fatigue and attrition. There is little scientific evidence on which to base decisions about the optimal number of rounds [4]. Our decision to conduct two Delphi rounds was therefore based on previous published studies. For consensus to be reached, at least 70% of respondents in our study had to rate an element or domain as highly important (either '1' or '2'). This criterion was consistent with the 75% agreement suggested by Keeney and colleagues in their review of the Delphi technique in nursing research [24]. Determining consensus by level of agreement is meaningful when Likert-type scales are used [19]. A response rate of at least 70% is recommended for Delphi studies to reduce the possibility of bias [25]. This was achieved and exceeded in both survey rounds.

Use of the Delphi technique captured a wide range of views by protecting the anonymity of respondents. However, the sample was biased towards females and respondents based in New South Wales; priorities may differ in other populations. Another limitation was the length of the questionnaire, which included many domain elements, raising the possibility of order effects and respondent fatigue. The domains and elements of patient experience

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presented in the first Delphi survey were derived from a scan of the literature, which is a recognised alternative approach to a qualitative initial round [4, 23]. To enhance consumer participation, it may have been better to start with consumer focus groups to generate items; this is the approach taken for the Dutch Consumer Quality Index [26]. Nevertheless, the inclusion of a wide range of experts, including consumers, in the expert panel strengthens the current study [18] and may promote acceptance of the final suite of indicators.

The commissioning organisation required a set of 20 prioritised indicators. Although it is not feasible to implement so many indicators immediately, the list captures a broad range of important aspects of patient experience, providing scope for a staged implementation approach. The four most highly ranked indicators are most likely to be suitable for large-scale implementation (for example at State level). The indicators with moderate levels of endorsement may have potential for use by individual services seeking to improve specific aspects of cancer care. Eight indicators were endorsed by 39% or less of the workshop sample which suggests they may not be such a high priority for implementation.

A patient centred quality cancer system is responsive to the needs of patients, carers clinicians and health systems [27]. Good outcomes are defined in terms of what is valuable to the individual patient [27]. To serve this purpose, it is essential that patient experience indicators for cancer care are meaningful, measurable and modifiable. Monitoring these indicators must produce information to identify areas for service improvement and make a difference to the way cancer services are delivered and, ultimately, to cancer patient experiences. Consequently, as a second step in the development process, the 20 draft indicators were presented to three workshops for further refinement and prioritisation. A physical meeting following the last Delphi round is an acceptable strategy for exchanging views and resolving uncertainties, as long as the meeting is well structured and moderated to contain the influence of dominant personalities [4].

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The priorities in the final suite of indicators (Table 4) were highly consistent with those established during the surveys. For example, *coordinated care*, the highest priority indicator, was based on the “Coordinated and Integrated Care” domain which was most highly rated of all domains in both surveys. This indicator focuses on care processes including assistance with navigating the health system; it excludes two elements which, based on the cluster analysis and workshop discussions, became separate indicators: *needs assessment* and *follow-up care/survivorship*. The domain “Timeliness of care” rated second in both surveys; at the workshops, this split into two indicators, both highly ranked: *timeliness of first treatment* and *timeliness of diagnosis*. The cluster analysis suggested the two domains of “Patient centred communication” could be combined, resulting in the highly ranked indicator *communication*, which covers issues of respect, treating patients with dignity and considering their needs and preferences. Another aspect of patient-centred care, focusing on participation and empowerment, formed a separate indicator: *shared decision making*. Two domains relating to information provision, each with many elements, were distilled down to four indicators: *information provision: side effects; care plan; information style (comprehensibility)* and *information provision (tailored and accurate)*. Despite the changes in wording and emphasis, the priority given to these issues in the workshop rankings largely reflects their domain and element ratings in the surveys, providing further confirmation that consensus has been achieved.

The Delphi data and multivariate analyses were used to suggest measurement tools for some of the indicators, supported by an evidence-based rationale [28]. Further work is necessary to support implementation, which may include a review of information systems and patient experience measures to identify relevant data items and develop new data items where required. There is a need for research to examine the extent to which measurement of

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an indicator may contribute to change in service provision and patient outcomes and to identify mechanisms by which processes of service delivery affect patient outcomes.

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CONFLICTS OF INTEREST

Funding for the research was provided by the Cancer Institute of New South Wales, Australia. The authors have no potential conflicts of interest directly or indirectly related to the research. All primary data are held by the authors.

ETHICAL APPROVAL

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

INFORMED CONSENT

Informed consent was obtained from all individual participants included in the study.

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Table 1 **List of domains**

	Domains of patient experience included in the Delphi survey
1	Comprehensiveness of information provided to patients
2	Style of information provision (e.g. whether written, understandable, consistent, etc.)
3	Patient centred communication by doctors
4	Patient centred communication by nurses and other health professionals
5	Technical expertise and knowledge of health professionals
6	Coordination and integration of care
7	Timeliness of care
8	Patient (or advocate) involvement in shared decision making
9	Provision of psychosocial guidance to patients
10	Comfort factors
11	Safety aspects
12	Sensitivity to special needs groups by services
13	Patient concerns about access to care
14	Assessment of patient experience and satisfaction by services

Table 2 Delphi participants' gender, state / territory and expert category

	Round 1		Round 2	
Demographics	N	%	N	%
Gender				
Male	28	19	21	19
Female	121	81	91	81
State / territory				
Australian Capital Territory	1	1	0	0
New South Wales	114	76	87	78
Northern Territory	0	0	0	0
Queensland	9	6	7	6
South Australia	10	7	6	5
Tasmania	1	1	1	1
Victoria	10	1	8	7
Western Australia	3	2	2	2
Other	1	1	1	1
Expert category				
Healthcare professional	57	38	37	33
Consumer - patient	25	17	22	20
Consumer – carer	19	13	17	15
Academic/technical expert	48	32	36	32
TOTAL PARTICIPANTS	149	100	112	100

Table 3 Ratings for most important elements in Round 2 survey, by domain

Element name	N (R2)	Mean (R2)	SD (R2)	% rated 1 or 2
Coordination and integration of care				
There is a well organised process of patient care through the care pathway including all treatment modalities	109	1.38	0.64	95
There is a holistic assessment of the patient's physical, psychosocial, supportive care and practical assistance needs	109	1.49	0.70	94
The patient is allocated a central point of contact to help coordinate their care across their pathway of cancer treatment	109	1.53	0.88	92
The patient is assisted and guided in trying to navigate the health system as it pertains to their care	109	1.75	1.06	89
The patient is referred to supportive services in a timely manner	109	1.73	0.78	93
The patient receives regular follow-up care (surveillance and monitoring) after active treatment is completed*	109	1.65	0.61	93
Timeliness of care				
The time between receiving confirmation of a cancer diagnosis and the commencement of the first cancer treatment	110	1.33	0.59	96
The time to receive a confirmed diagnosis (e.g. from GP referral to confirmation of diagnosis)	110	1.45	0.79	95
Patient centred communication by doctors				
Effective communication by doctors	107	1.37	0.83	94
Doctors consider the patient's preferences and needs	107	1.49	0.83	92
Doctors' answers to patient questions can be easily understood	107	1.57	0.97	89
Doctors treat the patient with respect and dignity	107	1.48	0.93	90
The patient has confidence and trust in the doctor(s)	107	1.57	0.99	90
Doctors encourage the patient to ask questions	107	1.67	1.05	89
Comprehensiveness of information provided to patients				
Information on treatment options including benefits and risks	107	1.21	0.58	96
Information on results of treatment and prognosis	107	1.39	0.72	93
Information on test results and diagnosis	107	1.45	0.90	90
Information on potential side effects, both short- and long-term	107	1.41	0.69	94
Information on pain management	107	1.48	0.78	91
Information on medication(s) use	107	1.59	0.74	89
Information on self-care and warning signs that may require the doctor's attention	107	1.50	0.77	93
Patient centred communication by nurses and other health professionals				
Effective communication by nurses	107	1.62	0.96	89
Nurses treat the patient with respect and dignity	107	1.48	0.93	91
Other health professional and hospital staff treat patients with respect and dignity	107	1.57	0.88	92
Nurses consider patient's preferences and needs	107	1.75	0.87	89
The patient has confidence and trust in nurses	107	1.74	1.02	89
Technical expertise and knowledge of health professionals				
Patients' confidence and trust in the doctors' knowledge and expertise	109	1.56	0.81	88
Patient (or advocate) involvement in shared decision making				
The patient feels their own preferences are taken into account when treatment decisions are made	110	1.57	0.76	92
The patient feels empowered by health professionals to take part in making	110	1.59	0.91	91

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Element name	N (R2)	Mean (R2)	SD (R2)	% rated 1 or 2
decisions about their care and treatment				
Patient concerns about access to care				
Patients from regional, rural or remote areas do not report disruption to or delays in their treatment plan due to their location	110	1.41	0.55	97
The patient has adequate access to chemotherapy services	110	1.36	0.66	96
The patient has adequate access to radiotherapy services	110	1.39	0.68	96
The patient has adequate access to specialist physicians	110	1.37	0.68	96
The patient has adequate access to hospital inpatient services	110	1.52	0.71	94
Safety aspects				
It can be demonstrated that the patient is supported in managing their pain safely (including medication and other therapies)	110	1.52	0.87	90
It can be demonstrated that the patient's medication is regularly reviewed and monitored	110	1.6	0.85	91
Provision of psychosocial guidance to patients				
The patient's psychosocial needs are addressed	110	1.41	0.75	96
The patient is referred, when appropriate, to relevant psychosocial support services	110	1.40	0.67	94
Style of information provision (e.g. whether written, understandable, consistent, etc.)				
Patients receive accurate information about their cancer care	107	1.34	0.85	95
Information provided is easy to understand	107	1.36	0.57	95
Patients receive the amount of information they need	107	1.79	0.92	90
A care plan for each treatment modality is recorded in the patient's medical record	107	1.48	0.82	93
A copy of the care plan for each treatment modality (e.g. chemotherapy, radiotherapy etc.) is shared with the patient	107	1.55	0.82	93
Assessment of patient experience and satisfaction by services				
Information regarding patient experiences is collected by the service and used to improve the organisation and delivery of care*	111	1.54	0.74	91
Sensitivity to special needs groups by services				
Interpreters are available for patients when needed	110	1.43	0.94	93
Extra assistance is provided for people with other disabling or chronic conditions	110	1.7	0.91	88
The health professionals are sensitive to differences in cultural perceptions of cancer and its treatment*	110	1.82	0.87	88
The health professionals are sensitive to differences in the needs of other special groups (e.g. elderly, people with disabilities, those with low health literacy, those experiencing social disadvantage, etc.)*	110	1.52	0.74	92
Comfort factors				
Where applicable, practical and logistical issues (e.g. travel, accommodation, scheduling of appointments) are addressed so that patients can more easily access the facilities where they are receiving care	110	1.65	0.80	88

Note. R2 = Round 2 (second survey). *These items were added or modified for Round 2 of the Delphi survey. Low scores indicate high importance.

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Table 4 Domains in order of importance*

Domain	Round 1					Round 2				
	N**	Mean rating	SD	% rated 1 or 2	% ranked top 2	N**	Mean rating	SD	% rated 1 or 2	% ranked top 2
Coordination and integration of care	138	1.39	0.71	92	38	112	1.38	0.8	95	51
Timeliness of care	138	1.43	0.71	94	26	112	1.43	0.69	95	39
Patient centred communication by doctors	138	1.54	0.88	90	35	111	1.49	0.86	94	27
Comprehensiveness of information provided to patients	138	1.55	0.81	88	29	112	1.57	0.81	91	10
Patient centred communication by nurses and other health professionals	138	1.78	0.98	83	15	111	1.65	0.84	93	8
Technical expertise and knowledge of health professionals	138	1.97	1.2	76	20	111	1.71	0.91	90	31
Patient (or advocate) involvement in shared decision making	138	1.78	0.99	79	11	112	1.73	0.9	89	8
Patients' concerns about access to care	138	1.96	1.08	74	3	112	1.84	0.87	82	7
Safety aspects of care	138	1.99	1.29	70	8	112	1.88	0.97	79	7
Provision of psychosocial guidance to patients	138	1.78	0.93	79	2	112	1.94	1.02	82	2
Style of information provision (e.g. whether written, understandable, consistent, etc.)	138	1.92	1.06	75	7	111	1.98	0.95	82	2
Assessment of patient experience and satisfaction by services	138	2.07	1.07	70	4	112	2.06	0.91	79	6
Sensitivity to special needs groups by services	138	2.03	1.17	72	0	112	2.13	1.04	69	0
Comfort factors associated with care	138	2.49	1.22	57	0	112	2.44	0.94	61	0

Note. * Order of domains is based on Round 2 mean ratings. Low scores indicate high importance. ** Round 1 rankings n=137, Round 2 rankings n=107.

Table 5 Final suite of prioritised cancer patient experience indicators

Rank*	Indicators in rank order**	% Ranking in top 10
1	Coordinated Care: Patients were provided with a coordinated process of care throughout their cancer treatment pathways.	96
2	Access to Care: Patients had appropriate access to all necessary modalities of cancer treatment for their cancer (e.g. clinical, surgical, chemotherapy and radiotherapy services).	80
3	Timeliness of First Treatment: The time between patients receiving confirmation of a cancer diagnosis and the commencement of their first cancer treatment (i.e. the treatment interval) was reported.	75
4	Communication: Patients experienced excellent communication from health professionals during their most recent cancer treatments.	71
5	Follow-up Care / Survivorship: Patients were provided with a follow-up care plan (including self-management strategies) that identified the health professionals responsible for their care following completion of their major cancer treatments.	63
6	Timeliness of Diagnosis: The time taken for patients to receive a confirmed cancer diagnosis (i.e. the 'diagnostic interval', from the first presentation to the GP or other medical practitioner) was reported.	57
6	Information Provision (Side-effects): Information was provided to patients (and/or their carers) so they knew how to manage common side-effects from their most recent cancer treatments.	57
8	Information Style (Comprehensibility): The service provided cancer patients with individually tailored information that they were able to understand.	55
9	Needs Assessment: Patients' health care needs were assessed during their cancer treatment pathways and responded to when needed.	51
10	Provision of Psychosocial Care (Patients): Patients' psychosocial needs were assessed and, when relevant, referrals to support services occurred during their most recent cancer treatments. Provision of Psychosocial Care (Carers): Carers' psychosocial needs were assessed and, when relevant, referrals to support services occurred.	47
11	Shared Decision Making: Patients felt as involved as they wished to be in sharing decisions about their most recent care and treatments for cancer.	45
11	Information Provision (Tailored and Accurate): Patients received individually tailored and accurate information from health care professionals on diagnosis, cancer stage and type, treatment and prognosis for their most recent cancer treatments.	45
13	Access (Location): Patients did not experience unnecessary or inappropriate delays in access or disruptions to their cancer treatment(s) due to their location.	39
14	Patient Experience: Information on patients' experiences of cancer treatment was collected at least annually, including an analysis of service complaints and compliments, and this	37

PATIENT EXPERIENCE INDICATORS

Rank*	Indicators in rank order**	% Ranking in top 10
	information was used to improve service delivery.	
15	Access (Logistics): Logistical issues for patients (e.g. travel, accommodation) were addressed when scheduling appointments, to facilitate patient access to cancer treatments.	37
16	Doctor's Knowledge and Expertise: Patients felt confidence and trust in the doctor's knowledge and expertise for their most recent cancer treatments.	33
17	Care Plan: Patients were engaged in the development of their care plan for each cancer treatment modality they experienced and the care plan was entered into their medical record.	29
17	Safety (Pain): Patients' pain was assessed and patients felt supported in managing their pain safely (including medication and other therapies) during their most recent cancer treatments.	29
19	Safety (Medication): Patients' medications were monitored during their most recent cancer treatments.	27
20	Priority Population Groups: Individually tailored support was provided as needed for cancer patients from priority population groups (e.g. patients from CALD communities, patients with other disabling conditions, patients experiencing social disadvantage).	25

Note. * Bold indicates that final ranking was within the top 10 indicators. **Ranking based on combined data from all participants in the three consultation workshops, n=51. Where percent data is the same for two indicators they are given the same priority ranking.

PATIENT EXPERIENCE INDICATORS

Figure 1 Ranking of the 20 draft indicators by workshop participants (n=51)

Note. The proportion of participants who ranked a draft indicator in their top three (their three most important indicators) is represented by the black areas. Dark grey and mid-grey have been used to indicate the proportion of participants ranking an indicator 4th to 7th and 8th to 10th respectively. The light grey tails at the right of each bar represent the proportion of participants who did not assign a top ten ranking to that indicator.